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# State Council for Developmental Disabilities

## Program Performance Report

### For Year 2018

State Council for Developmental Disabilities

## Section I: Identification

\* - Required input

To provide identifying information of the reporting Council

**1. State/Territory\***

Massachusetts

**2. Federal Fiscal Year Reporting\***

2018

**3. Contact person regarding PPR information\***

Daniel Shannon

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**6. Executive Director name (if different from contact person)**

**7. Executive Director's phone number\***

617-770-7676

**8. Executive Director's email address\***

dan.shannon@mass.gov

## Section II: Comprehensive Review and Analysis

\* - Required field

### **Adequacy of health care and other services, supports and assistance that individuals with developmental disabilities in Intermediate Care Facilities (ICF) receive**

Massachusetts continues to serve individuals in its six Developmental Centers. These centers provide 24-hour support in compliance with federal regulations. Massachusetts assists individuals and families who choose to move to homes in the community. In addition, the Office of Medicaid makes available a Residential Waiver for individuals who need a residential placement that has supervision and staffing, 24 hours a day, seven days a week due to significant behavioral, medical, and/or physical support needs and the absence of available, natural, generic and Medicaid services. The Waiver is a program run by the Commonwealth of Massachusetts through MassHealth that pays for health care for people living in Massachusetts who have medium, low, or no income.

### **Adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities served through home and community-based waivers receive**

**The vast majority of people with disabilities in Massachusetts live with their families.** Massachusetts offers specialized services and supports including: day supports, employment supports, residential supports, family supports, respite, and transportation. Massachusetts provides specialized services and supports to approximately 32,000 adults with intellectual disabilities and children with developmental disabilities. Currently, the Department of Medicaid in Massachusetts is serving more than 8600 children with developmental disabilities and their families.

MassHealth provides health care benefits to low- and moderate-income people with disabilities. MassHealth offers benefits directly, or by paying part or all of your other health-insurance premiums. Each waiver has a limit on the number of people who can be served in a waiver year. In addition, the Department of Developmental Services has the authority to limit enrollment into the waivers based on availability of funding for new waiver participants. Below are a description of the waivers made available in Massachusetts:

**The Children's Autism Home and Community-Based Services Waiver Program:** The Autism Waiver Program at the Department of Developmental Services Autism Division serves children, birth through age 8, with an autism spectrum disorder who meet the eligibility criteria. Only 157 children may participate in the Autism Waiver Program at any one time. The Autism Waiver allows children to receive Expanded Habilitation, Education, in-home services and supports, such as Applied Behavioral Analysis (ABA) and Floor Time, for a total of 3 years. At the conclusion of the 3 years of the intensive in-home services, a child may access ongoing Supplemental Services (for example respite and goods and services, etc.) that meet the child's needs and help with the transition out of the intensive Autism Waiver Program— until the child's 9th Birthday. All waiver services require that the child (and the child's family) continues to meet the financial and clinical eligibility requirements for the Waiver Program, 150% of the Federal Poverty Level (FPL).

**Community Living Waiver:** provides services to individuals who meet the eligibility criteria and require at least one home and community based waiver service per month. These individuals require more support than those in the Adult Support Waiver, but less than those in the Intensive Support Waiver. These individuals either live in the family home, adult foster care, with a live – in caregiver or independently and do not require 24 hour care. Their health and welfare needs can be met either in the family home or in the community. Waiver services may differ depending on the living arrangement of the individual. An individual will only receive services that are needed in order to remain safely in the community. The Community Living Waiver can support participant direction offering both budget and employer authority for specific services if the individual is interested.

**Adult Supports Waiver:** provides services to individuals who meet the eligibility criteria and require at least one home and community based waiver service per month. These individuals do not require the amount of services provided under either the Community Living Waiver or the Intensive Supports Waiver. These individuals live in the family home, adult foster care, or independently and do not require 24 hour care. Their

health and welfare needs can be met either in the family home or in the community. Waiver services may differ depending on the living arrangement of the individual. An individual will only receive services that are needed in order to remain safely in the community. The Adult Supports Waiver can support participant direction offering both budget and employer authority for specific services if the individual is interested.

## Section III: State Plan Implementation

\* - Required field

### A. Introduction

**Provide an executive summary with cohesive information that provides an overview of the report including, but not limited to the following: (1) targeted areas of emphasis, (2) strategies used to implement activities; (3) significant accomplishments and/or barriers to state plan implementation; (4) needs requiring state plan amendments**

The Council is on track to meeting the overall goals projected in the 5 year state plan. The continued focus is four goal areas as indicated in the plan: Self-Advocacy/Leadership, Supporting Families, Inclusive Communities, and Exercising Rights. The Council is making effective progress towards each goal area as indicated across all state plan narrative reports, consumer satisfaction surveys and data. Through a robust social media campaign, all social media targets were exceeded across all objectives.

The first Goal focused on providing people with DD/IDD and their families with the skills and information needed to engage in self-advocacy, systems –advocacy and leadership. The Council conducted trainings for youth and adults with DD/IDD, in addition to family members. The Council taught the Self-Advocacy Leadership Series (SALS) 9 times all across Massachusetts, graduating 98 transition-aged youth and adults. Due to cuts in appropriations, the Council was unable to meet the high demand of schools requesting SALS to be offered in their locations. The Council is starting to address this through the development of the SALS “Train the Trainer” program. This program is an intensive training that teaches students who have graduated from the SALS and displayed leadership potential how to become certified MA DD Council SALS trainers. This will allow for the SALS to be taught to more students in various geographical locations across

Massachusetts. The Council partnered with MA Advocates for Children, MA Advocates Standing Strong, and the Federation for Children with Special Needs on trainings targeted towards cultural diverse populations. Trainings were held on understanding the parent and student role in the IEP process. The Council was on the Planning Board for the annual Youth Leadership Forum held at Bridgewater State University. The conference is a one day, cross disability conference for MA youth in their final 2 years of high school. The majority of the trainings were taught by young adults with DD/IDD who are employed or enrolled in Higher Education. Seventeen disability organizations were involved in the collaboration, with 30 youth participants.

Opportunities to utilize advocacy and leaderships skills were made available through Council events such as the annual Legislative Reception held in March. The Governor attended and issued a Proclamation publicly recognizing March as ID/DD Awareness month. Several legislators were in attendance to meet with individuals and families. Six hundred and Twenty-Four people with DD/IDD participated in Council supported Self-Advocacy and leadership trainings. Of those who completed the Council's satisfaction survey, 90% reported that they now participate in advocacy activities.

The Council led various initiatives to meet the overall goal around people being able to exercise their rights and be safe in the community. The activities focused on two areas: Voting and Guardianship. The Council continued to have to lead the partnership with the Disability Law Center, REV Up, and other advocacy organizations to increase the number of individuals with developmental disabilities who are registered to vote. The Council and its partners continued to promote the Massachusetts' RevUp website and distribute RevUp voting pamphlets at disability related conferences. The Council's legislative Advocacy training developed in FY17 was taught by a young man with an Intellectual Disability to FY18 Independence College Students. Safety of people with ID/DD has been addressed in three ways: legislatively, abuse awareness trainings, and

guardianship. The Council was invited by the Legislature to deliver a report on abuse occurrences in group home settings and recommendations on systemic change to address the challenges. Funding was also provided to MA Advocates Standing Strong to teach its' Awareness and Action and Rights 101 classes, which resulted in the Council increasing the number of PWDD in developing awareness and safety skills as well as the promotion of safety and rights of PWDD. The Council continues to take a leadership role in the Guardianship working group of advocates, guardians, providers, attorneys and others to develop strategies to address full guardianship issues and supported decision making. Several meetings were held throughout the year at the Council's office with key stakeholders. The group is on track for the FY19 plan to develop an informational document outlining resources available to individuals and family members who are unsatisfied with guardianship decisions and proceedings. Two hundred and four people with DD/IDD participated in Council supported initiatives on voting, abuse prevention and decision making/rights. Ninety-Five percent of people with DD/IDD that completed the Council's satisfaction survey reported participation increase in rights and safety advocacy activities.

children from birth through 21, adults and older individuals with FASDs; to institute affordable evidence-based FASD interventions; to increase identification of individuals at risk of FASD so that FASD-informed services might impact their life trajectory; and to promote parent/youth navigators and coaches. The Council is working with the group to establish a grass roots coalition effort and legislative advocacy training. The group drafted a bill and received a commitment from both a state representative and senator to file bills that expand Department of Developmental Services (DDS) eligibility to all people with DD/IDD. The bill will be filed in quarter two of FY 19 when the legislative session begins. Three hundred and eleven family members participated in Council supported activities to increase their knowledge of family supports.



**Cultural Diversity : Describe the Council's overall efforts to address the needs of individuals with developmental disabilities and their families of a diverse culture through its state plan supported activities**

The Council supported various trainings targeting culturally diverse parents and individuals with DD/IDD. The Council was successful at diversifying its outreach for Independence College training program. 57 percent of the Council's Independent College participants self-disclosed as being either African American or Latino. The Council awarded a grant to Massachusetts Advocates for Children (MAC) to train underserved Latino families and youth with disabilities from linguistic and cultural minority families. The goal of the project was to increase active participation of underserved families and transition age youth in IEP meetings by developing curricula and conducting workshops. Nine trainings for parents were held; eighty-two parents participated. The youth trainings were taught by a self-advocate from the Dominican Republic. The young adult conducted 10 trainings. 116 youth, including 90 from linguistic, cultural, and racially diverse communities, completed the trainings. The Council also worked with the Autism Housing Pathways to develop accessible/affordable housing-related trainings materials to culturally diverse populations. Materials were translated into six languages to meet a diverse population: Arabic, Chinese, Haitian Creole, Portuguese, Spanish, and Vietnamese. Lastly, the focal point of the Council's grant to the Federation with Special Needs was to present special education training to 100 Haitian Creole speaking parents and transition aged young adult to empower them during the IEP process.

**B. Evaluation of State Plan Implementation**

**B1. Evaluation Activities**

The Council utilized a variety of evaluation methodologies that were best suited to reflect the overall progress being made in each specific activity. Each state plan goal and objective has identified strategies, activities, outputs and expected outcomes. The Council distributed pre training surveys and post training surveys to participants in Council taught and/or funded trainings. The Council educated people with disabilities and families about disability related events, self-advocacy, parent support, inclusive communities, and guardianship through our Facebook and Twitter page. We tracked each posts' data metrics (views, reactions, comments, shared) to determine if the post was successful in educating the target population.

The Council hosted its' annual legislative reception and surveyed attendees about their satisfaction with the event. In addition, each meeting scheduled with Legislators educating on the intent of a piece of legislation was documented. The Council tracked all follow up questions and also, how a particular legislator voted on a bill after meeting with the Council. Regarding our Rev UP voting initiative, the Council tracked the number of people with disabilities that registered to vote through the Rev Up website. Lastly, all of the workgroup meetings attended by Council staff were tracked, in addition to the number of Council developed information that was disseminated to attendees at various Council presentations and exhibit tables.

## **B2. Evaluation Results**

The Council continues to utilize the Developmental Disabilities Suite (DD Suite) project management system for tracking and reporting all Council projects and activities. This provides an effective mechanism for reviewing the current status of all objectives on a quarterly basis, or more often, if needed. This also allows at-your-fingertip access to cumulative data across fiscal years. The Council is on target in meeting the numerical goals indicated across all state plan objectives, in addition to qualitative data across each of the four goal areas identified in the state plan. In FY 18 alone, the Council received 470 responses to satisfaction surveys. 96.7% of respondents were satisfied with their participation project activities. Both numbers report an increase from FY 17 in terms of completed surveys and consumer satisfaction.

## **B3. Lessons Learned and Future work of the Council**

The Council continues to work through data collection barriers specifically around obtaining data from various multicultural populations and youth. Although surveys are translated into Spanish, many Council projects focus on other multicultural populations where neither English nor Spanish are clearly understood in written

form. The challenge with collecting post survey data from youth in high school that participate in Council advocacy trainings such as SALS and Independence College is that they often provide their school emails, if any emails at all. The schools are often not supportive in providing student contact information due to privacy issues. The Council will need to find new ways to capture post survey data from both populations. In addition, the Council has been working closely with MA Department of Education to discuss HiSet preparation and alternative options to a traditional diploma for students with disabilities. The HiSET® exam is one of three tests U.S. states and territories use to measure high school equivalency skills. Massachusetts' does have a portfolio path for those students who are unable to successfully pass the Massachusetts Comprehensive Assessment (MCAS). Based on our findings, we were unaware that this is not a viable option for students with ID/DD, rather, the portfolio initiative is used with students with health care needs who are unable to participate in a traditional classroom/testing setting. It is also used with students with high anxiety around test taking. The question remains whether this program can be utilized with ID/DD students. In FY 19, the Council will continue to work with students, parents, and the Department to find alternative solutions for students who are unable to pass the traditional MCAS.

#### C. Input on National Priorities

##### **Input on National Priorities**

ABLE Accounts are tax-advantaged savings accounts for individuals with disabilities and their families. These include costs, related to raising a child with significant disabilities or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare. ABLE Accounts allow individuals and families to establish savings accounts that will largely not affect their eligibility for SSI, Medicaid and other public benefits. The legislation explains further that an ABLE account will, with private savings, "secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary's employment and other sources." ABLE accounts were first made available in Ohio in 2016 and since then, 29 additional states have introduced ABLE accounts. Roughly 14,000 ABLE accounts have been open, yet experts say that millions more could benefit. The Council suggests that AIDD work to promote the benefits of the ABLE account to people with DD/ID and their families.

## Section IV: State Plan Implementation Progress Report

### Detailed Progress Report on Goals

#### Description

Advocacy and Leadership

#### Area Of Emphasis

Area of Emphasis	Planned for this goal	Areas addressed
Quality Assurance	true	true
Education and Early Intervention	true	true
Child Care		
Health		
Employment		
Housing		
Transportation		

Area of Emphasis	Planned for this goal	Areas addressed
<b>Recreation</b>		
<b>Formal and Informal Community Supports</b>		

#### Strategies

Strategies	Planned for this goal	Strategies Used
<b>Outreach</b>	true	true
<b>Training</b>	true	true
<b>Technical Assistance</b>		
<b>Supporting and Educating Communities</b>	true	
<b>Interagency Collaboration and Coordination</b>	true	true
<b>Coordination with Related Councils, Committees and Programs</b>		
<b>Barrier Elimination</b>	true	true
<b>Systems Design and Redesign</b>		
<b>Coalition Development and Citizen Participation</b>	true	
<b>Informing Policymakers</b>	true	true

Strategies	Planned for this goal	Strategies Used
Demonstration of New Approaches to Services and Support		
Other Activities		

### 3. Intermediaries/Collaborators

Collaborators	Planned for this goal	Actual
State Protection and Advocacy System	true	true
University Center(s)	true	true
State DD agency	true	true
MA Advocates Standing Strong	true	true
Boston Public Schools	true	true
Higher Education Programs	true	
Partners for Youth with Disabilities	true	true
MA Advocates for Children	true	true

Provide an overall cohesive description of (a) the extent to which progress is being made in achieving the intended outcomes of the Goal for the reporting year, (b) the extent to which each goal was or was not achieved for the reporting year, (c) where applicable, factors that impeded goal achievement for the reporting year, (c) needs that require substantive state plan amendment (goal only)

The Council made significant progress in achieving the intended outcomes for Goal #1: Advocacy and Leadership. Overall, the council met and or surpassed expected outputs and outcomes. The one area that posed a challenge was the ability to report any specific stories of culturally diverse people with developmental disabilities being impacted due to a barrier of data collection in compiling demographic information from individuals who participated in Council supported activities.

In FY18 the Council increased the number of self-advocate leaders participating on cross disability/ culturally diverse leadership coalitions through a grant to MASS to provide trainings in partnership with the Council's Independence College initiative. The Council further supported individuals and families through its Council Empowerment Program whereas the program financially supported individuals and family members to attend various events, trainings, and conferences in Massachusetts and outside of the state.

The Council increased the number of people with developmental disabilities and families becoming leaders through its partnership with MASS, as people with developmental disabilities joined the MASS board, became MASS members, and joined self-advocacy groups, including the Supported Decision Making task force. The Council also took part in planning the 2018 Statewide Transition Conference at Holy Cross College in Worcester, where families were introduced to state-of-the-art best practices around transition, covering topics that focused on creating seamless, successful transitions into the adult world. In addition, the Council collaborated with the Institute for Community Inclusion (ICI), the E.K. Shriver Center/UMASS Medical School, and the Disability Law Center in providing the Gopen Fellowship. The Fellowship fosters the leadership capability of an individual with developmental disabilities by supporting their development of a project in their area of interest and building the Fellow's personal and leadership advocacy skills. The Council provided \$20,000 in funds to support two Gopen Fellows in 2018. One fellow worked toward increasing access to advocacy services and peer support to underserved populations. The second Gopen Fellow's project focused on educating law enforcement personnel about interacting with and assisting people with disabilities. The Council also supported the Crocker Fellowship, which is for family members of people with developmental disabilities. The 2018 Crocker Fellow's project focused on inclusive recreation for school-aged children with developmental disabilities. The Council was able to further increase the number of people with developmental disabilities and family members becoming leaders in disability advocacy throughout 2018 through these efforts.



The Council participated in activities designed to assist adults with developmental disabilities in developing and engaging advocacy skills through the partnership with Massachusetts Advocates Standing Strong (MASS), the statewide self-advocacy organization. Trainings were offered through the Council's Independence College initiative and MASS designed to increase engagement and advocacy for PWDD. The Council also offered the Self Advocate Leadership Series (SALS) to adults utilizing 2 MDDC training teams and a partner team created through the Train the Trainers allowing for expanded leadership training within the state.

MDDC is currently in partnership with school districts in three out of five state regions. Our current partnerships include: Bridgewater State University in the southeast region with 14 sending school districts, AIC- American International College Holyoke Community College, UMASS Springfield our west region with 10 sending districts. The Boston Public School system which represents our Metro region district has 8 participating schools. In FY 18 a total of 9 trainings were delivered to both adults and students with disabilities. In total, 198 PWDD were trained through the SALS.

**4 Year Overview : A description of how the Council will use and build from knowledge gained and progress made to move forward in the next state plan cycle.(This section only applies to the PPR submitted for the Federal Fiscal Year 2020, which will be due by January 1, 2021)**

**5 Year Overview :** For the final PPR of this state plan cycle, provide an overall analysis of the outcomes achieved during the five year state plan cycle. The description should include the extent to which diverse stakeholders are satisfied with council activities that promote self-determination and community participation for individuals with disabilities and families, results of other types of information gathering such as focus groups, surveys, or other feedback or input methods with individuals with developmental disabilities and families and major accomplishments and factors impeding goal achievement (if applicable).(This section only applies to the PPR submitted for the Federal Fiscal Year 2021, which will be due by January 1, 2022)

#### Objectives

1. A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.

1. **Goal:** Advocacy and Leadership

2. **State Plan Objective** Objective 2

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3. **This Objective is**

Individual & Family Advocacy

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4. **This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	Yes
b. Targeted disparity *	No
c. DD Network Collaboration *	No
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

**6. Stage of Implementation**

Implementation

**7. Provide an overall description of this effort**

The Council participated in activities designed to assist adults with developmental disabilities in developing advocacy skills and helping them engage in advocacy in 2018. The Council achieved this through partnering with Massachusetts Advocates Standing Strong (MASS), the statewide self-advocacy organization, to offer trainings through the Council's Independence College initiative. MASS also held various trainings and conferences throughout the state designed to increase engagement and advocacy for PWDD. The Council also offered the Self Advocate Leadership Series (SALS) to adults in FY18, with the Train the Trainers series proving to be particularly successful.

## 8. Outputs Achieved

Expected Outputs	Achieved
2 adult SALS Classes will be held 20 Students will participate in SALS 16 Independence College classes will be held (2 of each) 25 Students will participate in Independence College 20 Students will complete the Independence College practicum. 20 family members will support students through participation in the SALS and Independence College programs. 4 opportunities for systems advocacy will be provided. 10 social media posts on Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

In FFY 2018 a total of three Independence College programs were offered by MDDC in partnership with M.A.S.S. A total of 30 out of 44 enrolled students graduated from the I.C. program. Independence College is an education opportunity for people with developmental disabilities eighteen years and older to take classes that will further their development towards independence. MDDC works in partnership with Massachusetts Advocates Standing Strong, our statewide self-advocacy organization. Currently, MASS has peer to peer training teams teaching seven of the eight classes offered. Peer to peer refers to people with disabilities serving as lead trainers to teach others with disabilities. MDDC is currently training 1 peer to peer training in a class called legislative advocacy. Students enrolled in the I.C. program are required to take 4 core required classes and a minimum of 2 out of four elective classes offered. The four core classes included Basic Self-Advocacy, Self-Direction, Choice and Control and Your Rights 101. The electives include the following: Explore Prepare Act, Awareness and Action, Voting and Basic Legislative Advocacy. All participants are also required to complete a practicum. The practicum is any goal the student chooses to explore and or complete that includes a number of action steps. Action steps can include but are not limited to making phone calls, attending meetings or conducting online research.

In FFY 2018 the I.C. executive team reduced the timeline of the I.C. program from a nine month program period to a four month program period. Condensing the time frame was done to keep classes and program responsibilities more consistent and in consecutive order to maintain student retention. This program change was well received by both trainers and participants. The practicum was found to be the

most challenging part of I.C. for students resulting in 10 students completing all core and elective requirements yet unable to graduate due the incompleteness of their practicum. The practicum focuses on students setting out to change or try something new. For some students, this can be challenging especially if they have minimal or poor support at home. Students remain part of I.C. and can choose to complete their practicum during future I.C. programs offered.

Massasoit Community College and the Harbor South office building served as venues where I.C. classes were held. During the February graduation state senator Patrick O'Connor served as the keynote speaker and in June senator Walter Timilty served as the Keynote. A total of 145 members of the public were present for both graduation ceremonies that took place at the Neighborhood Club in Quincy, MA.

One of our newest Council members who is both a graduate of the SALS and I.C. programs spoke at this years' I.C. graduation as a guest speaker. Another graduate of I.C. Mary Bradley is doing well and following her dreams as a dog trainer. As part of Mary's I.C. final practicum, Mary pursued getting her certification in dog training. Today she is operating her own dog training business. Ashley Quick, another graduate of I.C. applied and was awarded the 2018 Barbara Wilensky Gopen Fellowship.

For participant surveys the results were as follows: There was a total of 30 graduates. Of those graduates 16 reported being female and 14 reported being males. The ethnic background was reported out of 30 graduates, 12 reported being white, 14 black, 3 Hispanic and 1 Asian.

#### Questions

- 1) Increased advocacy skills and abilities- all 30 responded yes
- 2) I am better able to say what I want to say/ say what is important to me. All 30 responded yes
- 3) I am now participating in advocacy activities. Out of 30, 13 responded yes
- 4) I am serving on a cross-disability coalition, political board out of 30, 11 responded yes
- 5) I am satisfied with this project activity. All 30 responded yes

The Self-Advocacy Leadership Series (SALS) is an eight week program that teaches people with developmental disabilities 18 years and

older the fundamentals of leadership. Each 2 hour class focuses on a different topic. Topics for the SALS include the following: Who I am, Communication, Feelings and Values, Self-Advocacy/Leadership, Team Building, Rules and Laws and Speech writing. Each class utilizes a variety of teaching techniques such as lecture, role plays, small and large group activities to reach a broad learning range of students taught. One major accomplishment in FFY 2018 was by our training partners through the train the trainers series. In the beginning of the year, the MDDC offered 10 SALS graduates an opportunity to learn how to teach the SALS to others through the Train the Trainers series. Offering a train the trainers series allows MDDC to share the series with participating partners who can intern continue to offer the series to others while the council expands to work towards other goals. Train the trainers was a 28 hour program taught to students over a 4 day period. Participating students were sponsored by a host agency. Each participating agency agrees to submit numbers of people trained through our partnership with them. Students who participated in the Train the Trainers Series received a refresher version of the eight weeks series followed by a lesson that demonstrates to students how to break down activities to teach to others. Three students who received a certificate of completion from the Train the Trainers Series were sponsored and supported by South Shore Support Services. The South Shore team began their forth SALS in September a requirement of the MDDC for trainers to become a certified MDDC trainer. Once completed all three trainers will be eligible to become MDDC certified trainers they are scheduled to complete their 4th series in the beginning of FFY 19.

With combined efforts from the MDDC and our training partners, a total of 43 people with disabilities graduated from the SALS, the train the trainer series and learned about leadership. A total of 145 members of the community learned about the series and council efforts. Total number of graduates surveyed overall was 23. The form was not officially being used by our training partners in period 2 and 3 therefore 20 people prior who were taught the series during that time were not surveyed using the new tool.

Out of 23 surveys 4 people stated they were on coalitions or boards and filled out the following: Self-advocacy group/ gay pride group/ Middlesex advisory board/ Minute man Arc Human Rights Committee and the Kiwanis club.

As a result of participating in the adult series 8 former graduates participated in a pilot training for an employment training currently created by council staff. The grads participated and critiqued activities over a 3 day workshop. Efforts are currently in the works to launch

an employment pilot series in FY2019.

In collaboration with the MDDC, Massachusetts Advocates Standing Strong (MASS) continues to build self- advocacy leadership, develop and utilize leaders in systems and individual advocacy and support people with disabilities to self-direct their services to become as independent as possible. MASS educated self-advocates and others on self-direction, and supported the Independence College Project through planning and by conducting trainings. MASS educated people with disabilities across the state about supported decision making and hosted peer discussions about its utility as a policy or a law in Massachusetts These activities increased the number of leaders involved in systems change and the number of our peers that have a voice and are active decision makers in their lives.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Increased knowledge about self-advocacy, improved advocacy skills. Increased knowledge about self-direction and systems advocacy. Increased # of individuals interacting with legislators and policy makers and networking with others.	true

**13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.**



With combined efforts from the MDDC, our training partners, and grantees pwdd have increased their knowledge of self-advocacy and are utilizing their leadership skills. Out of 23 surveys delivered through the SALS program 4 people stated they were on coalitions or boards and filled out the following: Involved in a Self-advocacy group/ gay pride group/ Middlesex advisory board/ Minute man Arc Human Rights Committee and the Kiwanas club.

In the Northeast, eight self-advocates made it a priority to attend the National Self Advocates Becoming Empowered Conference in June with former SALS grad Donna Jay presenting on Self Direction. Three members had never been to a national conference and were inspired to get more involved on the Statewide and National levels of self-advocacy as a result. In FY 18 Donna Jay, applied to be a LEND Fellow and is now participating in this session. The MDDC has provided key support for MASS Regional Coordinators to assist with the work of our Supported Decision Making Task Force in educating our members about this alternative to guardianship and including their voices in designing a model that reflects their concerns. This work, in the long run, will give more people with disabilities an alternative to guardianship and increase their support and freedom to direct their own lives.

In FY 18 the council is able to report 3 SALS graduates becoming SALS trainers through the train the trainer course offered by the council. Another SALS/ independence grad started her own business as a result of her practicum goal and two 2 SALS /IC grads exercised their public speaking skills as guest speakers for this years' I.C. graduation.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report additional stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities.

While the Council worked on changing policy through its policymaker education activities in other goals through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to adults with disabilities developing advocacy skills in 2018.

**2. A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.**

**1. Goal:** Advocacy and Leadership

**2. State Plan Objective** Objective 3

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**3. This Objective is**

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Individual & Family Advocacy

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**4. This Objective is**

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Ongoing

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**5. This Objective is**

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	The Objective is
<b>a. Fulfilling a Self-Advocacy DD Requirement *</b>	Yes
<b>b. Targeted disparity *</b>	Yes
<b>c. DD Network Collaboration *</b>	No
<b>d. A demonstration project of New Approaches to Services and Supports *</b>	No
<b>e. A demonstration of projects or activities *</b>	No

## **6. Stage of Implementation**

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Implementation

### **7. Provide an overall description of this effort**

The Council sought to increase the number of minority students with developmental disabilities developing and engaging in advocacy skills in 2018. The Council achieved this through a training series at McKinley Prep High School in Boston called RISE. Twelve classes were held at the therapeutic and sometimes short-term placement high school. Classes centered on effective communication, communication with law enforcement, friendships and relationships, bullying, and breaking the stigma of disability and disability rights in the workplace. The Council also offered SALS in Boston Public Schools to transition aged students in 2018. The Council awarded a grant to Massachusetts Advocates for Children (MAC) in 2018, which they utilized to train underserved Latino families and youth with disabilities from linguistic and culturally minority families to increase active participation in IEP meetings. The Council also awarded a grant to the Federation for Children with Special Needs, who partnered with the Haitian American Public Health Initiatives, Inc. (HAPHI). The two worked collaboratively to present special education training to Haitian Creole speaking parents and transition aged young adults. Through these efforts, the Council was successful in increasing the number of minority students with developmental disabilities developing and engaging in advocacy skills in 2018.

### **8. Outputs Achieved**

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Expected Outputs	Achieved
<b>4 Youth SALS Classes will be held 40 Latino and African American students will participate in SALS. 4 opportunities for systems advocacy are provided 1 IEP training project implemented by grantee. 40 Latino and African American students and 40 family members trained in the IEP and education rights. 10 social media posts on Twitter and Facebook.</b>	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

The RISE (Realizing Independence and Self-empowerment) project held 12 classes at McKinley Prep High School beginning in November 2017. The class consisted of twelve students, meeting for two hours in a round table classroom setting. Classes consisted of introductions, ice breakers and setting expectations, effective communication, communicating with law enforcement, friendships and relationships, boundary setting, bullying, saying no to peer pressure, navigating conflict between peers, breaking the stigma of disability, disability rights in the workplace, writing

resumes and interview skills. Guest speaker Sergeant Shana Cottone speak to the class about communicating with law enforcement and Mental health counselor Beth McGinn spoke about crisis management, coping mechanisms, and crisis resources..

Some feedback provided by the students and educators included; "I like that I can come here to speak my mind". "We can agree and disagree with each other here". "I learned how to walk away from certain situations". "This training was one of the best things this year". "You helped us to develop new skills" "helped me to grow more as a person". "We built trust". Additionally, teacher Ms. Pomerence emailed that "this training made me a better educator." Teacher Ms. Campbell communicated "It seems that the RISE program had a huge impact on our students. We look forward to its continued success."

In partnership with the Boston Public schools STRIVE program, the MDDC offers the SALS program to public school students in transition ages 18-22. STRIVE Coordinators worked closely with Council staff to connect the program with school personnel and their students. A series for 3 public high schools was completed in April 2018. The 3 schools included Charlestown High, Urban Science Academy (USA) and Madison Park High. 14 students graduated and 15 members of the community learned about the SALS and council efforts.

Massachusetts Advocates for Children (MAC) received \$20,000 in MDDC grant funds and provided \$3,086 in matching funds to train underserved Latino families and youth with disabilities from linguistic and cultural minority families. The goal of the project is to increase active participation of underserved families and transition age youth in IEP meetings by developing curricula and conducting workshops.

Project staff have developed a linguistically and cultural appropriate training curriculum for Latino Spanish-speaking

parents of children with DD. The training incorporates video, questions, and active discussion throughout to engage participants. The trainer asks participants to identify concerns they have with the special education services their own children are receiving, so that those concerns can be addressed as examples in the training. The curriculum is focused on the crucial role of parents throughout the special education process, language access rights in special education, and immigrant rights in education, including resources for parents whose rights have been infringed upon based on their national origin. Two versions of the training were developed, one focusing on basic rights in special education, and the other on school districts' role in preparing students with DD for life after high school.

Substantial outreach was conducted to community-based, health, and disability organizations serving Latino families. Nine trainings were held with Latino parents serving as co-facilitators. 82 parents participated in the nine trainings and were very engaged throughout. Parents offered positive feedback on the surveys. Some of the survey comments were that the workshop "taught us to lose the fear of speaking for [our children] and advocating for them," "there should be more workshops like this one," and "I feel very happy because through [this workshop] I have learned a lot about what I can do for the well-being of my son." 35 of the 36 parents that submitted a survey reported having increased their advocacy skills and abilities.

MAC also worked with a self-advocate trainer to develop a training curriculum and conduct workshops for underserved youth between the ages of 13-22. The training focused on the importance of student participation in the IEP process for successful transition outcomes, and provided "hands on" activities in order to engage the youth. Intensive outreach was made to schools, youth agencies, and partners from diverse communities. The self-advocate, a young man with an intellectual disability from the Dominican Republic who is bilingual, conducted eight trainings during the year in Boston

Public Schools, at Partners for Youth with Disabilities (PYD), in Boston Asian YES, in Lawrence Public Schools and in Burlington.

116 youth attended ten trainings, including 90 from linguistic, cultural, and racially diverse communities. The youth were all engaged throughout the presentation and most participated during the “ice-breaker activity” and again when asked if they wanted to share their “take away” ideas. Responses provided during the discussion include: I learned that I should share my goals of wanting to go to cosmetology school; I learned I should be invited to my Team meeting and let them know I want to go to college; I learned I need to express myself at the meeting; I learned I need to make people understand what I want; I learned to speak up at meetings and let them know I want to go to college and study video development; Let them know I want to work in a day care center; I need to learn to advocate for the Ride.

Over 1/3 of the youth responded to surveys sent after the presentation. 72% stated they increased their advocacy skills and abilities and 79% said they are better able to say what is important to them.

The Federation for Children with Special Needs ("Federation") and the Haitian American Public Health Initiatives, Inc. ("HAPHI") worked collaboratively to present special education training to 100 Haitian Creole speaking parents and transition aged young adults. The goal of this training was to educate families about the special education process and their rights so they would feel empowered to actively participate in the IEP development during Team meetings. The partners received a \$20,000.00 grant from the Council and provided \$2,000.00 in match funds.



Several workshops were offered on Understanding Basic Rights in Special Education and the Individualized Education Program (IEP). Two one-on-one IEP clinics were held to review IEPs and provide feedback, two workshops held on Transition Planning and one on self-advocacy for Haitian youth. Using the cultural broker model, two Haitian Creole speaking parents were trained and mentored to provide culturally and linguistically appropriate training to other parents. 143 people participated in this initiative (97 parents, 24 professionals and 21 youth). Two additional webinars were created: one on the IEP and Special Education Parental Rights; and the other on the Transition Planning Process. The webinars will be available on both the Federation and HAPHI websites, allowing broader access to the Haitian Creole speaking community. The Federation training material was adapted and translated for the target population.

Outreach to a community that is largely isolated and feeling stigmatized was the leading challenge. The project networked with community and faith-based agencies to establish workshop locations that would be comfortable and welcoming to parents. Outreach was conducted through the Haitian media Radio Concorde to inform parents about the Federation-HAPHI special education project, and the Brockton Arc, where Haitian families congregate and are enrolled in Family Support Centers, as well as school districts with a high concentration of Haitian students; Haitian faith-based organizations and our statewide partners.

Haitian families learned about the importance of knowing their basic rights and their role and responsibilities concerning their children's education. They learned why family advocacy and self-advocacy are critical to their children's educational achievement. The March Federation Vision of the Community conference provided a unique opportunity for

Haitian parents learn from one another and address issues tailored to their children’s educational needs. 17 parents attended the conference. Based on feedback, the conference enabled parents to share their experiences and gain a deeper understanding of the barriers and issues facing them as a community.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Increased knowledge about self-advocacy, improved advocacy skills. Increased # of individuals interacting with legislators and policy makers and networking with others. Increased # of Latino and African American individuals with developmental disabilities effectively advocate for services in their IEP. Increased # family members effectively advocate for services in their child's IEP.	true

**13. Progress towards achieving outcomes for overall objective :** The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

Through a grant with the Federation for Children with special needs, Haitian families learned about the importance of knowing their basic rights and their role and responsibilities concerning their children’s education. They learned why family advocacy and self-advocacy are critical to their children’s educational achievement. Through participants’

feedback, HAPHI learned that there is a strong need for parent/professional support for parent advocacy and self-advocacy in order for ongoing and direct involvement of the family in the school's special education process to occur. HAPHI realized there is a need for more bilingual/bicultural support, and a greater network of Haitian families and Haitian-American professionals to facilitate positive interactions between schools and parents. At the end of the grant, a Haitian Creole speaking parent was hired to call each adult participant, who attended the training and provided contact information, to obtain feedback on the survey provided by MDDC.

To evaluate the training, participants were asked to fill in pre- and post-training evaluations to determine how much the participants increased their knowledge and ability to advocate for their children. Of the 69 participants who completed the pre-workshop survey, 52% said their knowledge of the topic was either poor (14.49%) or fair (37.68%). Of the 73 participants who completed the post-workshop survey, 91.78% said their knowledge of the topic had increased to excellent (57.53%) or very good (34.25%).

The council plans to improve their data collection among diversified populations to generate a better grasp of developed skills and improved engagement in both self-advocacy and systems advocacy. Data was difficult to achieve among student in the transition SALS and RISE program. Many chose not to complete survey forms. The council plans to improve communications with schools and guardians to collect data.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report of any stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. While the Council worked on changing policy through its policymaker education activities in other goals through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to youth with developmental disabilities developing advocacy skills in 2018.

**3. A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.**

**1. Goal:** Advocacy and Leadership

**2. State Plan Objective** Objective 1

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**3. This Objective is**

Individual & Family Advocacy

**4. This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	Yes
b. Targeted disparity *	No
c. DD Network Collaboration *	No
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

## **6. Stage of Implementation**

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Implementation

### **7. Provide an overall description of this effort**

The Council sought to increase the number of youth with developmental disabilities in developing advocacy skills and engaging in disability advocacy in 2018. The Council achieved this by offering the SALS for youth in transition, which targets students aged 18-22 in local high schools throughout Massachusetts. The Council offered this series in 3 out of 5 state regions through local school districts. The Council partnered with Bridgewater State University, American International College, Holyoke Community College, UMASS Springfield, and the Boston Public School system. The Council's annual legislative reception with the Arc of Massachusetts was also held in 2018, which brought 250 individuals to the State House in Boston to celebrate 40 years of the legislative reception. The youth in attendance were encouraged to meet with their legislators and tell their stories following the event. The Council also continued its collaboration with MASS and offered trainings and conferences to youth throughout the state designed to increase youth advocacy skills and engage youth in advocacy opportunities. The Council also played a key role in the 2018 Youth Leadership Forum, which brought high school students from across Massachusetts together to pursue resources and trainings that will be useful to them as they make their transition to higher education. Through these efforts, the Council was able to increase the number of youth with developmental disabilities in developing advocacy skills and providing them with various opportunities to engaged in disability advocacy in 2018.

### **8. Outputs Achieved**

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Expected Outputs	Achieved
4 Youth SALS Classes will be held 32 students will participate in SALS 25 Youth participate in the Youth Leadership Forum. 4 opportunities for systems advocacy are provided 10 social media posts on Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

The Self-Advocacy Leadership Series (SALS) for youth in transition targets students ages 18-22 in local high schools throughout the state of Massachusetts. In FY 18 SALS partnered with Bridgewater State University with students from 14 school districts, AIC- American International College Holyoke Community College and UMASS Springfield with students from 10 districts, and Boston Public Schools with students from 8 districts.

In FY 2018, two SALS training teams conducting SALS to 53 people with developmental disabilities. 41 students graduated from the SALS and the additional 12 students were in attendance for an in-school presentation, where one of our lead trainers shared their personal story about the struggles and triumphs of living with a disability.

One student who graduated from the series speaks to the power of SALS. This young woman from Brockton High School came to the first class with her head lowered and sometimes down on the table covering her face. She wouldn't speak nor make eye contact. As the series progressed she slowly began to express herself. Her voice became louder over time and her demeanor starting to show confidence. She shined during the communications portion of the series where she practiced showing the difference between passive, aggressive and assertive communication styles. Another SALS Grad has been studying with a famous local artist Donna Estabrooks. She shows and sells her art work at fairs and galleries, and has been asked to display her work at a prominent hospital. The SALS gave her the confidence to talk about her work and refine her salesmanship skills. Another SALS grad was hired in FY18 to work on the M.A.S.S. training team as a trainer for Awareness and Action.

Council staff participated in an Interagency Transition Team meeting and educated 15 people from diverse agencies on council opportunities. An additional 10 parents were educated about council efforts at a Youth and Transition Parent Support Meeting. An additional 100 people were present for the transition fair and learned of council efforts. In all 132 members of the general public were in attendance for all five SALS graduations that took place throughout western Mass. Council staff participated in an Interagency Transition Team meeting and educated 15 people from diverse agencies on council opportunities.



The intra-agency Transition team consists of a comprehensive support network for Western Mass agencies and providers to work together to collaborate and share ideas between districts, local partners and community agencies, improve student transition outcomes and identify community resources and share resources when possible. The groups that participated in the meeting included the Pioneer Valley Transit Authority (PVRTA), Mass Rehabilitation Commission, Agawam High principal and teachers, the Jewish Community Center, Multi-Cultural Community center and Massachusetts Advocates Standing Strong, the statewide self-advocacy group. Two connections were made with Holyoke transition academy and with the ICE coordinator for Holyoke Community College. Participation surveys were completed by 23 out of 53 SALS students. 22 indicated satisfaction with this project/ activity

In FY 18, the council participated in efforts to ensure that youth, adults, and family members with developmental disabilities engaged in self-advocacy. Specifically, 250 people attended the 40th Annual Legislative Reception hosted by the Council and the Arc of Massachusetts at the Massachusetts State House. Lauren Beckham Falcone of WROR Radio was the emcee. Of the 250 in attendance, 14 were youth with developmental disabilities. Since the event takes place during the school day, it is difficult to impact youth participation. Legislator of the year awards were presented to State Senator James Eldridge and State Representative Denise Garlick. Both legislators thanked the Council and the Arc for all of their hard work on behalf of people with disabilities in the Commonwealth, and pledged their continued support of people with disabilities. Angela Ortiz of the MA Pediatric Nursing Campaign spoke about the importance of making your voice heard and tied it into her personal experience of advocating on behalf of her medically fragile daughter. She spoke of her "fire" to advocate and encouraged those in attendance to "shine their light" on their legislators. Matthew Bander, Vice-chair of the Council, gave the call to action by speaking of his journey as a self-advocate and the importance of self-advocacy. Governor Charlie Baker spoke about the Commonwealth's commitment

to supporting people with developmental disabilities in the community and delivered the proclamation declaring March as Developmental Disabilities Awareness Month. The event ended with numerous attendees meeting with their legislators to discuss their issues and deliver literature relevant to the Council's priorities.

In collaboration with the MDDC, Massachusetts Advocates Standing Strong (M.A.S.S.) trained 165 people with disabilities to develop advocacy skills and engage in disability advocacy. M.A.S.S. worked with a variety of agencies and schools to provide a host of trainings to include, Basic Self-Advocacy, Awareness in Action, Explore Prepare ACT (EPA) and Self-Determination. Awareness in Action is a training on how to identify and report abuse and EPA is an employment training.

M.A.S.S. increased their presence at high-school transition fairs and programs throughout Metro, Southeast and Central regions of Massachusetts. In partnership with the council, M.A.S.S. provided training and Giving Back to Your Community with transition students from multiple high schools. Self-advocates presented to supporters and DDS staff about their lives and the kind of support they want -- at Area Offices, Service Coordinators' Institutes, Citizen Advisory Groups and at the DDS Leadership Training. Metro region self-advocates took part in a diversity day at the Boston Community Leadership Academy.

M.A.S.S. continued discussions with the Harvard Project on Disability to continue our work with them on Supported Decision Making. MASS Conference Committee Planning and preparations went into full swing as they selected workshops, finalized outreach and fundraising material and began to recruit sponsors, vendors and attendees for our conference celebrating MASS' 20th year. A total of 7 participated in council activities in partnership with MASS by

attending the Creating Your Vision event in October at a MASS event and partaking in the Merrimack Valley Task force event. MASS allocated \$11,250 of their \$60,000 Council grant toward this objective, providing \$1,142 in matching funds.

The 2018 Youth Leadership Forum (YLF) took place on Friday, June 29th at Bridgewater State University, with 30 high school students with disabilities and 3 young adults participating. 2018 YLF was a 1-day, cross-disability conference for Massachusetts youth in their final two years of high school. It provided young adults who attend college or are employed the opportunity to serve as peer leaders and offered participants training and resources that will be useful to them as they make the transition to higher education, work, and successful independent living as adults.

The forum began with ice breakers and small group discussions with peer leaders. After opening remarks, the attendees listened to presentations, met with career mentors and participated in an open mike wrap-up session. Presentations included disability pride and ableism, legislative advocacy and voting, employment and assistive technology. Resources were available from collaborators for leadership, empowerment and successful independent living.

After dropping off their children, parents had the opportunity to participate in a small group session with an adviser about transitioning to adulthood. MDDC staff helped with setting up and staffing the event. The MDDC's financial officer participated in the career mentoring session where he met with youth with disabilities and provided information about working in finance for a state government disability agency.

Seventeen organizations, including the MDDC, collaborated with lead organizer Partners for Youth with Disabilities to

plan and hold this event. Planning began in October at a collaborator meeting, with fourteen planning committee members in attendance. Members discussed 2017 YLF workshops and other successful event components, and brainstormed on how to improve the event for the future.

Until FFY 2017 YLF was an overnight, 4-day conference funded through a generous grant from the Massachusetts Rehabilitation Commission. In November the YLF Collaborators received word that MRC could not provide funding for 2018 YLF due to deep funding cuts. Collaborators remained committed to holding YLF and discussed the feasibility of holding a scaled down YLF for 2018.

In January Partners for Youth with Disabilities announced that the Department of Mental Health agreed to provide some funding to conduct a one-day, bare bones Youth Leadership Forum in June 2018. Collaborative partners met in January and March to plan the scaled down event, and there were regular subcommittee meetings to plan and organize presentations, recruiting and interviewing, and other details. Interviews with applicants took place by phone instead of face-to-face, and peer leader training was conducted by webinar rather than in person.

In May, the MDDC identified funding available to contribute to YLF and subsequently awarded a \$5,000 grant to Partners for Youth with Disabilities with \$10,502 in match funds. Additional information about the event along with output, outcomes and performance measure data is included in Partners for Youth with Disabilities' final grant report.

## **12. Expected Outcomes Achieved**

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Expected Outcomes	Achieved
Increased knowledge about self-advocacy, improved advocacy skills. Increased # of individuals interacting with legislators and policy makers and networking with others.	

**13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.**

While the MDDC has been successful in completing outputs for this objective collecting information for the outcomes posed a challenge in 2018. At the end of the SALS participation surveys were completed by 23 out of 53 students. Two out of the five series taught were not surveyed due to the tool being developed therefore 29 students didn't fill out the survey. For the following questions: I have increased my advocacy skills and abilities- 22 reported yes, I am better able to say what I want to say/ say what is important to me- 20 reported yes, ,I am now participating in advocacy activities- 21 reported yes, I am serving on Cross-disability coalition, policy board, advisory board or other leadership position that makes decisions for others - 2 reported yes, 21 reported no and 1 there was no answer. One student said they are one of the leaders on the Holyoke High School Unified Track team.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report additional stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. While the Council worked on changing policy through its policymaker education activities in other goals through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to adults with disabilities developing advocacy skills in 2018.

**4. A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.**

**1. Goal:** Advocacy and Leadership

**2. State Plan Objective** Objective 4

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**3. This Objective is**

Individual & Family Advocacy

**4. This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
<b>a. Fulfilling a Self-Advocacy DD Requirement *</b>	Yes
<b>b. Targeted disparity *</b>	No
<b>c. DD Network Collaboration *</b>	No
<b>d. A demonstration project of New Approaches to Services and Supports *</b>	No
<b>e. A demonstration of projects or activities *</b>	No

## **6. Stage of Implementation**

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Implementation

### **7. Provide an overall description of this effort**

The Council sought to increase the number of people with developmental disabilities and family members becoming leaders in disability advocacy in 2018. The Council achieved this through its partnership with MASS, as people with developmental disabilities joined the MASS board, became MASS members, and joined self-advocacy groups, including the Supported Decision Making task force. The Council also took part in planning the 2018 Statewide Transition Conference at Holy Cross College in Worcester, where families were introduced to state-of-the-art best practices around transition, covering topics that focused on creating seamless, successful transitions into the adult world. In addition, the Council collaborated with the Institute for Community Inclusion (ICI), the E.K. Shriver Center/UMASS Medical School, and the Disability Law Center in providing the Gopen Fellowship. The Fellowship fosters the leadership capability of an individual with developmental disabilities by supporting their development of a project in their area of interest and building the Fellow's personal and leadership advocacy skills. The Council provided \$20,000 in funds to support two Gopen Fellows in 2018. One fellow worked toward increasing access to advocacy services and peer support to underserved populations. The second Gopen Fellow's project focused on educating law enforcement personnel about interacting with and assisting people with disabilities. The Council also supported the Crocker Fellowship, which is for family members of people with developmental disabilities. The 2018 Crocker Fellow's project focused on inclusive recreation for school-aged children with developmental disabilities. The Council was able to further increase the number of people with developmental disabilities and family members becoming leaders in disability advocacy throughout 2018 through these efforts.



## 8. Outputs Achieved

Expected Outputs	Achieved
1 Fellowship grant awarded 1 Gopen Fellowship completed 1 Crocker Fellowship completed 1 Statewide transition conference held 40 family members participate in in the transition conference 4 Council and partner advocacy events 5 board, workgroup and other leadership opportunities 10 leaders participating in advocacy and on boards, etc. 10 social media posts on Twitter and Facebook	true

10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).

In 2018 108 people with developmental disabilities increased their knowledge of how to take part in decisions that affect their lives by joining the M.A.S.S. board, becoming M.A.S.S. members, joining self-advocacy groups, partaking in the Supported Decision Making Task force and by training DDS service Coordinators. The Council supported the MASS Supported Decision-Making Task Force, which explored avenues by which MASS might advocate for laws and policies that promote SDM.

78 new members attended the annual MASS Conference on September 15th. One new member applied and was elected as a Southeast Representative to the MASS Board and 20 new members have been recruited for self-advocacy groups in the Southeast. 3 Self advocates trained new DDS Service Coordinators at the Service Coordinator's Institute on MASS and understanding how they want to be supported.

In FY18, the Statewide Transition from School to Adult Life Conference was held at Holy Cross College, with 269 family members attending. The conference hosted families and introduced them to state-of-the-art, best practices around Transition, covering topics focused on creating seamless, successful transitions into the adult world. Self-advocates, professionals and parents shared their knowledge and experience in the transition process. 26 breakout sessions were provided ranging from secondary transition and Department of Developmental Services 101 to using assistive technology and autonomy, supported decision making and guardianship. The conference also included ambassadors with ID/DD in the workshops.

The planning committee met with 8 representatives the Council, the Arc, Northeast Arc, Brockton Arc, and DDS to discuss the event and suggestions to apply to the next conference. Post-conference surveys were discussed and recommendations made to improve the next conference. About 41 respondents of 200 parents filled out the post-

conference evaluation. There were 20+ diverse families in attendance and 25 scholarships were provided. It was agreed to organize exhibitors by region at the next conference as many regional organizations were present. It was also agreed to invite transition programs; simplify registration (sections); develop three strands: middle/HS/post-grad.

Overall, attendees were happy with the location and the group would like to stay at Holy Cross for the next conference. A majority of respondents responded positively to the question that the conference helped prioritize and identify next steps of Transition Planning and thought they received good direction in terms of transition planning out of this conference.

The Gopen Fellowship is a collaborative initiative of the Massachusetts Developmental Disabilities Network, comprised of the Council, the Institute for Community Inclusion (ICI) at the University of Massachusetts/ Boston, the E.K. Shriver Center/ UMass Medical School and the Disability Law Center. Based at ICI, the goal of the Gopen Fellowship is to foster the leadership capability of an individual with developmental disabilities by supporting the individual's development of a project in their area of interest and building the Fellow's personal leadership and advocacy skills. The work of two Gopen Fellows took place during FFY 2018. The Council contributed \$20,505 and ICI provided \$6,649 in matching funds.

Hala O'Keeffe served as the Gopen Fellow from July 2017 – June 2018. The goal of her Fellowship was to increase access to advocacy services and peer-support to underserved populations. Through her Fellowship, Hala trained four special education advocates in a disability rights model of advocacy, three of whom plan to continue this work. Among these were lower-income self/family advocates, self/family-advocates of color, and Department of Children and Families agency-involved families and individuals. The language of a "civil rights model" for special education advocacy, rather

than a “special needs model” was seen to be empowering for the families involved, as well as encouraging each family to view advocacy as something that would continue and develop through the lifespan. Not being solely focused on K-12 special education allowed each advocate to take a more holistic approach to the family as members of the disability community.

Hala was also able to match eight peer support teams to provide each other with mutual support assistance. This included accessing crisis services from organizations dealing with sexual assault and relationship violence. The staff of these organizations may not have had adequate training to communicate effectively with an individual with developmental disabilities seeking help. The three participants stated that they were not comfortable having to bring the issue to a specific disability professional or agency and were glad that the peer support advocate program allowed them the opportunity to make use of the services of organizations with a focus on crisis rather than disability.

At the mid-point of the fellowship year, Hala joined with several other self-advocates to found Inclusion Advocacy Collaborative (IAC), a 501 (c)3 organization based in Massachusetts, with chapters in Austin, Texas and Seattle, Washington. Hala’s Fellowship project exemplified the new organization’s mission, namely: “advocacy at the intersection of special education, disability rights and economic justice”. At the close of the Fellowship year, Hala was able to present a plan for maintaining the advocacy program in the future, and was asked to oversee the direction of IAC as its acting treasurer and director. After her Fellowship ended Hala stated, “For me personally, as well as for the self-advocate founders and steering committee of IAC, as well as the project participants, the Fellowship had a significant positive effect on activism, advocacy, and participation in the disability rights movement.”

Ashley Quick began her Gopen Fellowship in July, 2018. The goal of Ashley's project is to educate law enforcement personnel about interacting with and assisting people with disabilities. With support from Delta Projects in Dedham, Ashley spent the first quarter of her Fellowship at ICI gathering information about the types of training available to law enforcement and first responders. She researched the issues that impact interaction between police officers and people with various disabilities, including intellectual disabilities, Deafness, Autism and mental health. After her preliminary research, Ashley created a list of questions to ask police officers including the disability training they received, the types of training offered in their departments, how information is conveyed from caller to dispatch to police officers taking the call, their awareness ahead of time if the situation includes people with disabilities and how they respond to incidents in group homes. Ashley interviewed 3 police officers in Brewster, Randolph and Boston police departments during the quarter.

The Dr. Allen C. Crocker Family Fellowship is for family members of people with developmental disabilities, similar in scope to what the Gopen Fellowship offers. Melissa Kielbania was the Crocker Fellow from July 1, 2017 – June 30, 2018. Her project focus was on inclusive recreation for school-aged children with developmental disabilities. Upon completion of her Fellowship, Melissa joined the Council's board as a parent member. Raquel Quezada began her Crocker Fellowship in July. Raquel was awarded the Fellowship to produce and host a radio program to share information about disabilities, services and supports for Spanish-speaking family members of people with developmental disabilities.

For the Gopen and Crocker Fellowships, ten people (9/Hala + Ashley =10) with developmental disabilities participated in Council supported activities designed to increase their knowledge of how to take part in decisions that affect their lives, the lives of others, and/or systems. Six family members participated in Council supported activities designed to increase their knowledge of how to take part in decisions that affect the family, the lives of others, and/or systems.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
improved systems advocacy skills; Increased # of individuals people advocating with legislators and other policy makers Increased number of people participating as leaders on boards, committees, work groups, etc.	true

**13. Progress towards achieving outcomes for overall objective :** The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

While the Council succeeded in increasing the number of PWDD and family members being exposed to leadership opportunities in 2018, there is still more work to be done toward ensuring these individuals actually became leaders on boards, committees, work, groups, etc. One such barrier that will be addressed moving forward is ensuring that follow-up surveys ask these questions. In addition, the Council did not achieve the outcome of improving systems advocacy skills for these individuals, and will plan to address this during the remaining years of state plan implementation. The Council was successful in increasing the number of people advocating with legislators and other policymakers, as 2 Fellows participated in advocacy with legislators and policymakers in 2018 through these efforts.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report of any stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. While the Council worked on changing policy through its policymaker education activities in other goals through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to individuals becoming leaders in disability advocacy in 2018.

5. 50 self-advocate leaders will participate in cross-disability/culturally diverse leadership coalitions through September 30, 2021.

1. **Goal:** Advocacy and Leadership

2. **State Plan Objective** Objective 5

3. **This Objective is**

Individual & Family Advocacy

4. **This Objective is**

Ongoing

5. **This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	Yes
b. Targeted disparity *	No
c. DD Network Collaboration *	No



	The Objective is
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

## 6. Stage of Implementation

Implementation

### 7. Provide an overall description of this effort

The Council sought to increase the number of self-advocate leaders participating on cross-disability/culturally diverse leadership coalitions in 2018. The Council achieved this through offering a grant to MASS to provide trainings in partnership with the Council's Independence College initiative, where MASS would share leadership opportunities with students. The Council further supported individuals and families through its Council Empowerment Program in 2018. The program financially supported individuals and family members to attend various events, trainings, and conferences in Massachusetts and outside of the state. The Council also shared information on leadership opportunities via their social media feeds in 2018. Through these efforts, the Council was able to increase the number of self-advocate leaders participating in various leadership coalitions throughout 2018.

## 8. Outputs Achieved

Expected Outputs	Achieved
1 grant issued 4 people with developmental disabilities employed by MASS as trainers 8 opportunities for PWDD to provide trainings to other PWDD 50 people trained 4 opportunities for disability advocacy provided 6 MASS trainings to support Council's skills training initiatives 5 MASS self-advocates participate on cross-disability and culturally diverse leadership coalitions 10 social media posts on Twitter and Facebook	true

10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).

Massachusetts Advocates Standing Strong (MASS) utilized \$7,500 of a Council grant, providing \$761 in matching funds to provide 6 trainings in partnership with Independence College. The trainings offered included Self Direction; Basic Self Advocacy; Choice & Control; Explore, Prepare & Act; Awareness & Action; and Voting. These trainings expanded individuals' knowledge of basic self-advocacy. At these trainings, MASS shared leadership opportunities with students. During the first period of FY18, 1 self-advocate represented MASS on the DDS Regional Advisory Committee, and an additional 4 self-advocates served on the central area's DDS Citizen Advisory Board. During period 2 of FY18, MASS partnered with the Council's Independence College initiative for its spring semester. During this semester, 6 self-advocates took part in MASS' Rainbow Support Group, which partnered with Syracuse University in developing a tool to support relationships. An additional 3 self-advocates took part in a cross-disability committee and transportation committee held in Worcester. Period 3 of FY18 saw a continuation of trainings offered through Independence College, as well as various networking events. Specifically, MASS was present at high-school transition fairs throughout the state, a transition program which consisted of 2 self-advocacy classes and a diversity day at the Boston Community Leadership Academy. In the final period of FY18, 1 self-advocate who took part in Council supported trainings applied for and was rewarded a LEND Fellowship, which recruits trainees who desire to advance their knowledge and skills in preparation for a leadership role working with children with disabilities and other special health care needs and their families. Throughout FY18, the Council's support of MASS resulted in 15 individuals with developmental disabilities participating in Council supported activities designed to increase their knowledge and participate in cross-disability and culturally diverse coalitions. While collected survey data was an area that needs improvement, some data was collected that should be highlighted. Individuals were asked in follow-up surveys if they had used their knowledge gained through Council activities to participate on cross-disability coalitions, boards etc., and 1 individual responded that they had. In addition, of the 11 individuals who completed a satisfaction survey provided by MASS, all 11 of the respondents indicated they were satisfied with the Council supported activity.

The Council also supported individuals through its Council Empowerment Program. The program supported a total of 42 individuals to attend various events throughout the state and in places as far away as Ohio. The Council provided more than \$8,000 in funding to these individuals who participated in local events, trainings, and conferences.

The Council utilized social media platforms such as Facebook and Twitter to promote MASS and its efforts on behalf of people with developmental disabilities in the Commonwealth. The Council's projected output was 12 posts. This was exceeded by 142%. The Council's top viewed post of FY18 reached 1,658 people, which was a save the date for MASS' 20<sup>TH</sup> Annual Self-Advocacy Conference. The Council's social media efforts fostered a greater understanding of the work MASS and Independence College does on an everyday basis toward increasing self-advocates knowledge and confidence, leading to greater leadership opportunities throughout FY18 and beyond.

With a regional coordinator now working in the Southeast region of the state, MASS has increased its' connections with providers and individuals. At the annual MASS Annual Conference in Worcester national leader, Tia Nelis, spoke passionately about taking control of your life and working together to make supports better for everyone. In the Northeast, eight self-advocates made it a priority to attend the National Self Advocates Becoming Empowered Conference in June with a former SALS graduate presenting on Self Direction. Three members had never been to a national conference and were inspired to get more involved on the national level of self-advocacy as a result. In FY 18 one self-advocate applied to be a LEND Fellow and is now participating in this session. The MDDC has provided key support for MASS Regional Coordinators to assist with the work of our Supported Decision Making Task Force in educating our members about this alternative to guardianship and including their voices in designing a model that reflects their concerns. This work, in the long run, will give more people with disabilities an alternative to guardianship and increase their support and freedom to direct their own lives.

The goal of MASS' self-advocacy project is to promote and nurture self-advocacy in people with developmental disabilities such that they become meaningful decision makers in their own lives. MASS allocated \$18,750 of their \$60,000 Council grant toward this objective. MASS provided match funds of \$1,903.00.

Several students who took part in spring classes supported by MDDC at Northern Essex Community College attended their first self-advocacy group for youth in September. A participant in the February Supported Decision Making Conference went on to present her story at the national SABE Conference in Alabama this June and applied, and received, a LEND Fellowship this summer. In connection with M.A.S.S. events, a total of 5 members of the general public were made more aware of council's efforts and were in attendance for the Creating Your Vision event in October.

One area in need of improvement for M.A.S.S. was reconnecting with participants in Council supported activities to conduct and collect surveys. M.A.S.S. has developed new strategies to improve on this performance measure.

## **12. Expected Outcomes Achieved**

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Expected Outcomes	Achieved
MASS maintains a disability advocacy presence Increased number of new self-advocate leaders Increased support to self-advocate leaders Increased awareness of MASS Increased funding opportunities for MASS	true

**13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.**

The Council was particularly successful in achieving its expected outcomes for 2018 for this objective. The Council was successful in assisting MASS in maintaining a disability advocacy presence at various leadership coalitions throughout the state. In addition, the Council and MASS supported the establishment of new self-advocate leaders through sharing leadership opportunities in the various trainings offered throughout the state, as well as its participation in the Statewide Transition Conference, and via its social media efforts. Most performance measure data for this objective was reported by grantees under objective 4 in 2017 and 2018. This objective will be removed in 2019 and activities and outcomes will be reported under objective 4.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report of any stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. While the Council worked on changing policy through its policymaker education activities in other goals through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to individuals becoming leaders in disability advocacy in 2018.

## Individual & Family Advocacy Performance Measure

### Description

## Advocacy and Leadership

### Race/Ethnicity

Race/Ethnicity	#	%
White, alone	67	38.95
Black or African American alone	43	25
American Indian and Alaska Native alone	1	0.58
Hispanic/Latino	45	26.16
Asian alone	10	5.81
Native Hawaiian & Other Pacific Islander alone	0	0
Two or more races	2	1.16
Race unknown	4	2.33

### Gender

Gender	#	%
Female	63	42
Male	87	58



<b>Gender</b>	<b>#</b>	<b>%</b>
<b>Other</b>	0	0

#### Category

<b>Category</b>	<b>#</b>	<b>%</b>
<b>Individual with DD</b>	624	37.82
<b>Family Member</b>	1026	62.18

#### Geographical

<b>Geographical</b>	<b>#</b>	<b>%</b>
<b>Urban</b>	107	61.49
<b>Rural</b>	67	38.51

I. Output Measures

Objective	Performance Measure : IFA 1.1 People with DD who participated in activities	Performance Measure : IFA 1.2 Family members who participated in activities
<b>A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	73	152
<b>A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	163	194
<b>A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	265	266
<b>A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.*</b>	108	44

<b>Objective</b>	<b>Performance Measure : IFA 1.1 People with DD who participated in activities</b>	<b>Performance Measure : IFA 1.2 Family members who participated in activities</b>
<b>50 self-advocate leaders will participate in cross-disability/culturally diverse leadership coalitions through September 30, 2021.*</b>	163	0
<b>Total # of Output Respondents</b>	135	60

## II. Outcome Measures

<b>Performance Measures</b>	<b>Percent (%)</b>
<b>IFA 2.1 Percent of people with DD who increased advocacy</b>	57.8
<b>IFA 2.2 Percent of family members who increased advocacy</b>	100

Sub-Outcome Measures : The number (#) of people who are better able to say what they want/say what is important to them

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	45	0

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	60	23
<b>A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	18	0
<b>A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.*</b>	1	35
<b>50 self-advocate leaders will participate in cross-disability/culturally diverse leadership coalitions through September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	124	58

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>IFA 2.3 Percent of people better able to say what they need</b>	92	97

Sub-Outcome Measures : The number (#) of people who are participating in advocacy activities

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	44	0
<b>A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	61	23
<b>A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	19	0

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.*</b>	0	35
<b>50 self-advocate leaders will participate in cross-disability/culturally diverse leadership coalitions through September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	124	58
<b>IFA 2.4 Percent of people participating in advocacy activities</b>	92	97

Sub-Outcome Measures : The number (#) of people who are on cross disability coalitions, policy boards, advisory boards, governing bodies and/or serving in leadership positions.

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	1	0
<b>A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	0	0
<b>A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.*</b>	2	0
<b>A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.*</b>	1	0

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>50 self-advocate leaders will participate in cross-disability/culturally diverse leadership coalitions through September 30, 2021.*</b>	5	0
<b>Total # of Sub-Outcome Respondents</b>	9	0
<b>IFA 2.5 Percent of people on cross disability coalitions</b>		0

**IFA 3 The percent of people satisfied with a project activity\***

96.2

**IFA 3.1 Percent of people with DD satisfied with activity\***

95.2

**IFA 3.2 Percent of family members satisfied with activity\***

100

## System Change Performance Measures

**Description**



## Advocacy and Leadership

SC 1: Output Measures - The number of Council efforts to transform fragmented approaches into a coordinated and effective system that assures individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

Objective	SC 1.1 Number of policy/ procedures created/ changed	SC 1.2 Number of statutes/ regulations created/ changed	SC 1.3.1 Number of promising practices created	SC 1.3.2 Number of promising practices supported through Council activities	SC 1.3.3 Number of best practices created	SC 1.3.4 Number of best practices supported through Council activities	SC 1.3 The number of promising and/or best practices created and/or supported	SC 1.4 Number of people trained/ educated	SC 1.5 Number of Systems Change activities with other organizations
A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.	0	0	0	0	0	0	0	0	7

<b>Objective</b>	<b>SC 1.1 Number of policy/ procedures created/ changed</b>	<b>SC 1.2 Number of statutes/ regulations created/ changed</b>	<b>SC 1.3.1 Number of promising practices created</b>	<b>SC 1.3.2 Number of promising practices supported through Council activities</b>	<b>SC 1.3.3 Number of best practices created</b>	<b>SC 1.3.4 Number of best practices supported through Council activities</b>	<b>SC 1.3 The number of promising and/or best practices created and/or supported</b>	<b>SC 1.4 Number of people trained/ educated</b>	<b>SC 1.5 Number of Systems Change activities with other organizations</b>
<b>A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.</b>	0	0	3	3	0	0	0	59	3
<b>A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.</b>	0	0	0	1	0	0	0	0	1

<b>Objective</b>	<b>SC 1.1 Number of policy/ procedures created/ changed</b>	<b>SC 1.2 Number of statutes/ regulations created/ changed</b>	<b>SC 1.3.1 Number of promising practices created</b>	<b>SC 1.3.2 Number of promising practices supported through Council activities</b>	<b>SC 1.3.3 Number of best practices created</b>	<b>SC 1.3.4 Number of best practices supported through Council activities</b>	<b>SC 1.3 The number of promising and/or best practices created and/or supported</b>	<b>SC 1.4 Number of people trained/ educated</b>	<b>SC 1.5 Number of Systems Change activities with other organizations</b>
<b>A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.</b>	0	0	0	0	0	0	0	0	0
<b>50 self-advocate leaders will participate in cross-disability/ culturally diverse leadership coalitions through September 30, 2021.</b>	0	0	0	0	0	0	0	0	0

Systems Change SC 2: Outcome Measures

Outcome Measures	Number(#)
SC 2.1 - Efforts that led to improvements *	1
SC 2.2 - Efforts that were implemented *	0

Sub-Outcome Measures

Objective	SC 2.1.1 Policy, procedure, statute, regulation improvements	SC 2.1.2 Policy, procedure, statute, regulation implemented	SC 2.1.3 Number of improved promising or best practices	SC 2.1.4 Number of implemented promising or best practices
A minimum of 200 adults with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.	0	0	0	0

<b>Objective</b>	<b>SC 2.1.1 Policy, procedure, statute, regulation improvements</b>	<b>SC 2.1.2 Policy, procedure, statute, regulation implemented</b>	<b>SC 2.1.3 Number of improved promising or best practices</b>	<b>SC 2.1.4 Number of implemented promising or best practices</b>
<b>A minimum of 100 Latino and African American students with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.</b>	0	0	1	0
<b>A minimum of 100 youth with developmental disabilities will develop advocacy skills and engage in disability advocacy by September 30, 2021.</b>	0	0	0	0
<b>A minimum of 50 people with developmental disabilities and family members will become leaders in disability advocacy by September 30, 2021.</b>	0	0	0	0

Objective	SC 2.1.1 Policy, procedure, statute, regulation improvements	SC 2.1.2 Policy, procedure, statute, regulation implemented	SC 2.1.3 Number of improved promising or best practices	SC 2.1.4 Number of implemented promising or best practices
50 self-advocate leaders will participate in cross-disability/ culturally diverse leadership coalitions through September 30, 2021.	0	0	0	0

## Detailed Progress Report on Goals

### Description

Exercising Rights

#### Area Of Emphasis

Area of Emphasis	Planned for this goal	Areas addressed
Quality Assurance	true	true
Education and Early Intervention		
Child Care		
Health		
Employment		
Housing		
Transportation		
Recreation		
Formal and Informal Community Supports	true	true

#### Strategies

Strategies	Planned for this goal	Strategies Used
Outreach	true	true
Training	true	true
Technical Assistance		
Supporting and Educating Communities	true	true

<b>Strategies</b>	<b>Planned for this goal</b>	<b>Strategies Used</b>
<b>Interagency Collaboration and Coordination</b>	true	true
<b>Coordination with Related Councils, Committees and Programs</b>		
<b>Barrier Elimination</b>	true	true
<b>Systems Design and Redesign</b>	true	true
<b>Coalition Development and Citizen Participation</b>		true
<b>Informing Policymakers</b>	true	true
<b>Demonstration of New Approaches to Services and Support</b>		
<b>Other Activities</b>		

### 3. Intermediaries/Collaborators

<b>Collaborators</b>	<b>Planned for this goal</b>	<b>Actual</b>
<b>State Protection and Advocacy System</b>	true	true
<b>University Center(s)</b>		
<b>State DD agency</b>		true
<b>MA Advocates Standing Strong</b>	true	true



Collaborators	Planned for this goal	Actual
MA Guardianship Workgroup	true	true
MA Probate Court System	true	true

**Provide an overall cohesive description of (a) the extent to which progress is being made in achieving the intended outcomes of the Goal for the reporting year, (b) the extent to which each goal was or was not achieved for the reporting year, (c) where applicable, factors that impeded goal achievement for the reporting year, (c) needs that require substantive state plan amendment (goal only)**

The Council is making significant progress in achieving the intended outcomes for Goal # 4: Exercising Rights in 2018. The Council's Independence College initiative partnered with MASS and offered Awareness and Action and Rights 101 classes, which resulted in the Council increasing the number of PWDD in developing awareness and safety skills as well as the promotion of safety and rights of PWDD. However, there is still more work to be done toward further increasing these numbers and collecting additional follow-up data from participants in Council supported activities. The Council was also directly involved in educating policymakers regarding pieces of legislation relative to the safety and rights of PWDD through assisting Council members with testimony and accompanying them at meetings with legislators. However, some of the policy priorities selected by the Council members were impeded from advancing in the legislature and were sent to study in their relative committees. The Council also made significant progress in achieving its intended outcome of increasing the number of PWDD registered to vote in Massachusetts for FY18. The Council succeeded at this by collaborating with REV UP MA, the Disability Law Center (DLC), and other advocacy organizations that provided trainings, information and voter registration opportunities throughout Massachusetts. The Council partnered with the REV UP MA Campaign, which worked on registering more voters with disabilities, as well as educating voters and ensuring that each voter has the resources to vote and the knowledge of their voting rights. This was accomplished through forums, emails, and their website. However, finding exact numbers of PWDD voting for this first time as a result of Council activities was difficult to find, due to the data-collection barrier the Council faces. The Council is working on data collection techniques moving forward to obtain this information. The Council also made significant progress in assisting PWDD in pursuing alternatives to guardianship in FY18. Specifically, the

Council's social media presence helped increase PWDD's knowledge of the alternatives to guardianship, specifically Supported Decision Making (SDM). The Council, along with self-advocates at MASS, provided input on an SDM statute that is currently in the planning stages and will continue to provide input in FY19. In addition, through the GWG, the Council brought together stakeholders with policymakers at DDS to discuss, strategize and increase the awareness of guardianship issues to Massachusetts policy makers. The GWG also drafted language to amend Clinical Team Reports to help improve court practices in guardianship proceedings and submitted it to the Probate Court. The Council has still more work to do in their effort to improve court practices in guardianship proceedings, particularly when it comes to training individuals under guardianship and judges, which they plan to focus on in the remaining years of state plan implementation. At this time, there are no substantive state plan amendments needed for goal 4.

**4 Year Overview : A description of how the Council will use and build from knowledge gained and progress made to move forward in the next state plan cycle.(This section only applies to the PPR submitted for the Federal Fiscal Year 2020, which will be due by January 1, 2021)**

**5 Year Overview : For the final PPR of this state plan cycle, provide an overall analysis of the outcomes achieved during the five year state plan cycle. The description should include the extent to which diverse stakeholders are satisfied with council activities that promote self-determination and community participation for individuals with disabilities and families, results of other types of information gathering such as focus groups, surveys, or other feedback or input methods with individuals with developmental disabilities and families and major accomplishments and factors impeding goal achievement (if applicable).(This section only applies to the PPR submitted for the Federal Fiscal Year 2021, which will be due by January 1, 2022)**

## Objectives

1. A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.

1. **Goal:** Exercising Rights

2. **State Plan Objective** Objective 2

3. **This Objective is**

System Change

4. **This Objective is**

Ongoing

5. **This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	Yes
b. Targeted disparity *	Yes

	The Objective is
c. DD Network Collaboration *	Yes
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

## 6. Stage of Implementation

Implementation

## 7. Provide an overall description of this effort

The Council sought to increase the number of individuals with developmental disabilities who are registered to vote in Massachusetts in FY18. The Council succeeded at this by partnering with REV UP MA, the Disability Law Center (DLC), and other advocacy organizations who provided trainings, information and voter registration opportunities throughout Massachusetts. The Council partnered with the REV UP MA Campaign, which worked on registering more voters with disabilities, as well as educating voters and ensuring that each voter has the resources to vote and the knowledge of their voting rights. This was accomplished through forums, emails, their website, and a robust social media presence. The Council also utilized its Independence College initiative to further increase PWDD knowledge of the

importance of voting. The Council was successful in collaborating with other advocacy organizations to increase the number of PWDD registered to vote in Massachusetts, but exact numbers of new voters was difficult to determine in FY18. The Council is working on data collection techniques moving forward to obtain this information.

## 8. Outputs Achieved

Expected Outputs	Achieved
12 Rev Up initiative partners 1 Rev Up voting web page managed 6 Rev Up voter registration events held 12 Rev Up e-blasts 150 PWDD join the voting initiative through the Rev Up web page. 100 PWDD register to vote 50 PWDD vote for the first time 10 social media posts on Twitter and Facebook	true

10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).

The Council sought to increase the number of individuals with developmental disabilities who are registered to vote in Massachusetts in FY18. The Council succeeded at this by partnering with REV UP MA, the Disability Law Center (DLC), and other advocacy organizations that provided trainings, information and voter registration opportunities throughout Massachusetts. The Council partnered with the REV UP MA Campaign, which worked on registering more voters with disabilities, as well as educating voters and ensuring that each voter has the resources to vote and the knowledge of their voting rights. This was accomplished through forums, emails, and their website. REV UP staff attended voter forums, responded to requests; researched voting rights and rules, and worked to reach out to as many people with disabilities to ensure each one understands their rights in FY18. A voter forum was held in May, in which 25 people with developmental disabilities, 10 family members, and 65 “other individuals” participated in Council supported activities designed to increase their knowledge on their rights and the importance of voting. In addition, voter registration and education events were held in Braintree and Framingham where 20 more individuals with developmental disabilities, 30 family members, and 40 “other individuals” participated in Council supported activities. It’s also worth noting that local elected officials attended these events, resulting in 10 individuals being educated in through the Council’s systemic change initiatives. Through these efforts, individuals reported increasing their advocacy. Specifically, during period 3 of FY18, following May’s voter forum, 20 individuals responded to follow-up surveys that asked whether they increased their advocacy. In addition, 20 more individuals responded to the follow-up survey after the Braintree and Framingham events mentioned above. Of the 40 respondents to the follow-up surveys, a total of 38 individuals (20 from May’s voter forum, 18 from Braintree and Framingham events) reported that they increased their advocacy after participating in Council supported activities in FY18.

The Council also supported a voting class offered through Independence College. The class taught the importance of voting, how to vote, and voting rights. A total of 3 classes were offered, where 29 individuals with developmental disabilities participated in Council activities designed to increase their knowledge.

This brought the grand total of individuals participating in Council supported activities designed to increase their knowledge on voting and the importance of voting to 74 in FY18. In addition, the total number of family members who participated in Council supported activities in FY18 was 40, and the total number of “other individuals” was 105 in FY18. All data for this objective was found through registration records from these events.

The REV UP MA campaign also worked with the Council is expanding individual’s knowledge on the importance of voting through web-based strategies such as email and social media platforms in FY18. The email list increased to over 450 people receiving ongoing informative emails with important voter information and event announcements. The information included in these emails was overviews of the voting process, reminders of important dates and information about various events - both at venues and on television. During the fall, members received notice of disability forums and candidate debates. The REV UP MA website was updated frequently with similar information, making sure people with all different disabilities have the information they need to register, learn about candidates and be educated on the issues. Information was shared about disability issues to reinforce the importance of voting. There were several ballot questions to be voted on the election, and information explaining those questions was shared to individuals. This resulted in the website having approximately 33,000 unique visitors over the last year. The Council also partnered with REV UP to develop and distribute a brochure which provides people with disabilities an overview of registering and voting, and listed resources where they can learn more.

The Council also utilized social media platforms such as Facebook and Twitter to educate people on the importance of voting. Our projected output was 12 posts. This was exceeded by 142%. The Council's top viewed post reached 2425 people: The deadline to register to vote in the MA State Primary being held on September 4th is August 15th. The post directed people to a link where they were prompted to register to vote. The Council’s social media presence sparked an interest among people with disabilities in voting for the first time.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Improved collaboration to increase voting of people with developmental disabilities Increased number of people with developmental disabilities registered to vote Increased number of people with developmental disabilities voting for the first time.	true

### 13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

The Council was successful in collaborating with other advocacy organizations to increase the number of PWDD registered to vote in Massachusetts, but exact numbers of new voters was difficult to determine in FY18. The Council is working on data collection techniques moving forward to obtain this information.

### 14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).



The Council could not report of any stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. While the Council worked on changing policy through its policymaker education activities in other objectives under goal 4 through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to individuals with developmental disabilities voting for the first time as policy priorities in 2018.

**2. A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.**

**1. Goal:** Exercising Rights

**2. State Plan Objective** Objective 3

**3. This Objective is**

System Change

**4. This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	No
b. Targeted disparity *	No
c. DD Network Collaboration *	Yes
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

**6. Stage of Implementation**

Implementation

**7. Provide an overall description of this effort**

With a broadening consensus that guardianship can create barriers to independence for individuals with developmental disabilities, the Council supported and participated in efforts to assist these individuals in pursuing alternatives to full guardianship in FY18.

## 8. Outputs Achieved

Expected Outputs	Achieved
12 members collaborating on Guardianship Work Group 6 Guardianship Work Group meetings held 1 informational document on supported decision-making and alternatives to guardianship produced and disseminated 1 policy/practice developed 200 policymakers educated. 6 social media posts on Twitter and Facebook	

10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).

Founded by the Council, the Guardianship Working Group (GWG) met 6 times during FY18. There were 9 members, consisting of representatives from the MDDC, the DLC, Delta Projects, DDS, the Arc of Massachusetts, MHLAC, the Committee for Public Counsel Services, a guardian, and a family member attending these meetings. In an effort to improve collaboration on guardianship advocacy for people with developmental disabilities, the GWG hosted meetings which brought in 3 individuals from DDS. One such meeting was held on 10/12/17 and was attended by Marianne Meacham, the General Counsel at DDS, and her assistant, Sarah Peterson. The GWG compiled a list of 20 questions from Marianne, and Marianne did her best at providing answers at this meeting. The questions covered topics from DDS' role in guardianships to what DDS does when guardianships go wrong. Marianne gave a background of her work with DDS—she's responsible for the attorneys who work on guardianship issues in the state. She gave the group some data about guardianships in MA—the service population is 39,057 with 26,000 being served and 12,000 individuals under the age of 22, and 13,356 are under guardianship. Marianne reassured the group that DDS' stance on guardianships is that they be “the least restrictive as possible,” and that this has been made clear to the legal team at DDS. Marianne answered questions regarding when things go wrong/absentee guardians. She stated that these issues can be dealt with through the training of service coordinators, which DDS is currently looking into, and that if service coordinators are not prioritizing these issues, they need to be raised with DDS and they will do their part in working on resolving it. If paid guardians are unresponsive and absentee, then they should be removed. There is a policy and protocol that is followed when removing a guardian; anyone can initiate this process. Trainings were also discussed at this meeting. Marianne said that DDS does not provide training for paid guardians, as most of them are already lawyers. There is also no training for family members. The GWG anticipates establishing a line of consistent communication with DDS and plans to invite Sarah Peterson to be a regular attendee of the GWG in FY19.

The GWG also invited Rich Santucci, then Director of the Office of Human Rights at DDS to a meeting in June. The same issues discussed with Marianne were discussed. When things go wrong in a guardianship, Rich stated that there is a DDS document on guardianship that touches upon what individual's options are to challenge guardianships. In addition, sometimes if a guardian is not involved, there can be a request for them to resign, a lot of times removing the guardian is labor-intensive and time-consuming,

a lot of times if a guardian is asked to resign, they'll resign. One of the themes that resulted from this meeting was to think about extending the outline of what an individual's rights are under guardianship how they can go about exercising them.

The GWG continued to meet throughout FY18 and the topics that were consistently raised were the need for trainings of service coordinators, individuals under guardianship (what their rights are, what alternatives exist (SDM), etc.) and judicial training. There is a lack of training of these groups, and the GWG is currently in the planning stages of developing a "one size fits all" training curriculum for these groups, including the utilization of the Council's Independence College and Self-Advocacy Leadership Series (SALS) to include information in the courses offered through those initiatives. Another topic discussed at the meetings was the issue of Clinical Team Reports. The GWG crafted potential language to insert into CTR reports. Group members used their contacts at the Probate Court to see if they would be open to including that language. This is still in the planning stages, as the GWG member involved is waiting to hear back. The language would be the following: "Current understandings from neuroscience indicate people do not achieve full brain development until age 26 years. As such, guardianship orders established before this age will be automatically reviewed upon the individual's 26th birthday to determine if the existing guardianship decree remains appropriate." This would be relevant to all individuals under guardianship and would not single out individuals who have ID/DD. The GWG discussed alternatives to guardianship at their FY18 meetings, specifically the topic of Supported Decision Making (SDM). There is a group of lawyers and advocates drafting an SDM bill, and 2 members of the GWG are on that group providing input on the process. This legislation is still in the planning stages. In addition, the GWG discussed compiling a "Guardianship 101" document that would provide information on guardianship and the alternatives to guardianship that are available, such as SDM. Currently, a GWG member is in contact with an individual at Suffolk University Law School who is designing a kiosk that would be available at the Probate Court that would provide information on guardianships and alternatives. The GWG member is in talks with this individual to see what information is going to be available in this project and to potentially include that in the document. This is still in the pre-planning stages, and the GWG plans to address this in FY19.

The GWG plans to focus its work on developing trainings, participating in the SDM legislation effort, CTR language amendments,

and addressing when things go wrong in guardianships during FY19. The group also plans on inviting individuals from DDS to become members of the GWG, in an effort to establish a clear line of communication between the advocates, lawyers, and guardians on the GWG and DDS. In addition, the GWG plans to invite self-advocates to meetings to discuss their experiences within the guardianship system in FY19.

The Council participated in an SDM Legislative Group, which met 2 times in FY18. Those attending these meetings were 6 representatives from the MDDC, Greater Boston Legal Services, and The Center for Public Representation, the Northeast Justice Center, Massachusetts Advocates Standing Strong, and the Disability Law Center. An additional 2 self-advocates attended these meetings from MASS, bringing the total number of people with developmental disabilities participating in Council supported activities designed to increase their knowledge to 2 in FY18. These meetings centered on drafting a statute that would authorize SDM agreements for certain adults with disabilities in Massachusetts. The group agreed that input from self-advocates at MASS is important while drafting the legislation, as it would affect them the most. With that in mind, MASS held several meetings to discuss SDM and provided input to the drafters of the legislation, including a memo that expressed their concerns with the current draft. It was agreed upon that there needs to be an articulation of rights and a code of ethics and conduct for individuals who will be supporters. In addition, a mechanism for reporting suspected abuse/exploitation should be included in the statute, and those regulations should be handled by an agency with a broader scope, due to the fact that the statute would affect a large group of people from different backgrounds/needs. Self-advocates at MASS will continue to play a central role in the legislative group in FY19, as they plan to schedule meetings to gather input from their members. The group plans to reach out to legislative sponsors once that process is complete at MASS and hope to file a bill in January 2019. The status of the draft legislation is still in the planning stages at this time. With the efforts from the GWG and SDM legislative group, a grand total of 18 “other individuals” participated in Council supported activities designed to increase their knowledge in FY18. All data for this objective was found in attendance records from these meetings.

The Council also utilized social media networks such as Twitter and Facebook to increase knowledge of SDM and other alternatives to guardianship. The Council exceeded their goal of 9 posts in FY18 by 111%, with the most viewed post reaching 471 individuals/families. This post congratulated Massachusetts Families Organizing for Change (MFOFC) for being chosen to participate in the Center for Public Representation's pilot program on Supported Decision Making (SDM), which is an alternative to guardianship designed to empower people with disabilities to make choices about their own lives with the support of a self-appointed team.

Through the Council's efforts with the GWG and SDM legislative group, self-advocates and disability organizations were included in systems change activities, while increasing knowledge of the alternatives to full guardianship available in the Commonwealth.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Improved collaboration on guardianship advocacy for PWDD Increased knowledge of PWDD and family members about alternatives to full guardianship. Increased policymaker awareness of guardianship issues.	

**13. Progress towards achieving outcomes for overall objective :** The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

The Council made significant progress in assisting PWDD in pursuing alternatives to guardianship. Specifically, the Council's social media presence helped increase PWDD's knowledge of the alternatives to guardianship, specifically Supported Decision Making (SDM). The Council, along with self-advocates at MASS, provided input on an SDM statute that is currently in the planning stages and will continue to provide input in FY19. In addition, through the GWG, the Council brought together stakeholders with policymakers at DDS to discuss, strategize and increase the awareness of guardianship issues to Massachusetts policy makers. The GWG also drafted language to amend Clinical Team Reports to help improve court practices in guardianship proceedings and submitted it to the Probate Court. The Council has still more work to do in their effort to improve court practices in guardianship proceedings, particularly when it comes to training individuals under guardianship and judges, which they plan to focus on in the remaining years of state plan implementation.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report of any stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. While the Council worked on changing policy through its policymaker education activities in other objectives under goal 4 through legislation, there are no stories to report of any policy or legislative changes during 2018, as the Council 's membership did not select any legislation relevant to alternatives to guardianship policy priorities in 2018. However, the Council continued to



participate on a working group tasked with drafting a statute on establishing supported decision-making as an alternative to guardianship in Massachusetts during 2018, with plans to have the bill filed in 2019. The Council plans to continue to be active in this area in the remaining years of state plan implementation.

**3.** A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.

**1. Goal:** Exercising Rights

**2. State Plan Objective** Objective 1

**3. This Objective is**

Individual & Family Advocacy

**4. This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	Yes
b. Targeted disparity *	No
c. DD Network Collaboration *	No
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

**6. Stage of Implementation**

Implementation

**7. Provide an overall description of this effort**

In order for the Council to meet its overall goal of people with developmental disabilities exercising their rights, the Council planned to support various trainings designed to increase individuals with developmental disabilities' understanding of their rights. The Council's Independence College initiative partnered with Massachusetts Advocates Standing Strong (MASS) to provide trainings designed to expand individuals' knowledge of their rights and offered resources that will help them live safely in their communities. MASS was provided a grant from the Council, and this grant was used to design the aforementioned trainings. MASS also held a conference centered on rights under Supported Decision-Making, an alternative to guardianship. The Council was also heavily involved in educating policymakers about the importance of legislation filed in the Massachusetts legislature that would increase the safety of individuals with developmental disabilities. Council staff assisted Council members in drafting and providing testimony to the Joint Committee on Public Health, the Joint Committee on Children, Families and Persons with Disabilities, and the Joint Committee on Public Safety and Homeland Security. The Council also continued its social media presence by providing the general public with information relative to safety and rights of individuals with disabilities through Facebook and Twitter in 2018. While the Council succeeded in training PWDD in developing awareness and safety skills, in addition to promoting safety and rights of PWDD, there is still more work to be done toward further increasing those numbers and collecting additional follow-up data from participants in the remaining years of state plan implementation. MASS and the Council are developing strategies to improve in this area moving forward.

## 8. Outputs Achieved

Expected Outputs	Achieved
1 grant implemented to conduct awareness and action training for PWDD 50 PWDD trained 200 policymakers educated about rights and safety 1 strategy identified to conduct training with family members, guardians, and caretakers on promoting safety and rights 12 social media posts on Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

In order for the Council to meet its overall goal of people with developmental disabilities exercising their rights, the Council planned to support various trainings designed to increase individuals with developmental disabilities' understanding of their rights. The Council provided Massachusetts Advocates Standing Strong (MASS) with a grant of \$7,500, which MASS matched with \$761 to provide the aforementioned trainings in partnership with Independence College. The trainings expanded individuals' knowledge of their rights and offered resources that will help them live safely in their communities. With support from the Council, MASS continued their efforts in education on basic rights, self-advocacy, self-determination skills, and safety. Through Council supported activities, trainers from MASS were supported to teach 15 students in Awareness and Action, a class about abuse. In addition, a 2-hour class called Rights 101 was offered through Independence College, which covered the basic rights every individual with a disability, is guaranteed under the Americans with Disabilities Act (ADA) and how to apply those rights to everyday life. Resources were distributed to students for services such as Housing, Transportation, Vocational Rehabilitation (VR) Services and Accommodations, educating 24 students in this elective course through Independence College. In addition, 72 MASS members took part in a conference centered on rights under Supported Decision-Making, an alternative to guardianship. A total of 9 self-advocates also attended a forum centered on changes coming to MassHealth, along with 2 family members, which would end up

being the total for FY18 of family members participating in Council supported activities designed to increase their knowledge. Self-advocates from MASS learned of and expressed their opinions on their rights in regard to access to transportation at a hearing that focused on proposed cuts to regional transit authorities in Haverhill. A total of 5 self-advocates attended this hearing. In addition, 1 self-advocate attended a meeting of the Disabled Persons Protection Commission (DPPC)'s Advisory Board and used her knowledge of her rights to write a letter of support with MASS for a grant to make it more easy for individuals with disabilities to report abuse.

Other individuals were also involved in Council supported activities in FY18. As outlined below, a total of 29 policymakers were educated on the Council's policy priorities through the testimony of Council members. The DPPC established a Sexual Assault Response Unit (SARU) in Massachusetts and through the Council's grant funding, 4 staff members of MASS attended informational sessions regarding the purpose of SARU and its efforts across the state. As mentioned above, MASS held a conference on Supported Decision-Making in Massachusetts. This was attended by 23 supporters of individuals with developmental disabilities. An additional 12 provider and DDS staff attended the forum on MassHealth changes as well. This brought the grand total of "other individuals" participating in Council supported activities to 68 in FY18.

The Council was also directly involved in educating policy makers about important pieces of legislation promoting the safety of people with disabilities in their communities. Council staff assisted Council members in drafting and providing testimony on 3 of the Council's policy priorities at 3 separate legislative committee hearings. A total of 2 Council members with developmental disabilities participated in Council supported activities when they provided testimony to 12 legislators on the Joint Committee on Public Health, 8 legislators on the Joint Committee on Children and Families, and 9 legislators on the Joint Committee on Public Safety and Homeland Security. Council Member Kate provided testimony on SB. 1221: An Act creating autism teams in hospitals. The bill was heard on 10/24/17, Kate told of her personal experiences as an individual on the autism spectrum in hospitals to the Joint Committee on Public Health. Council Member Lydia provided testimony on H. 93: An act regarding the use of aversive

therapy, which would prohibit the use of procedures which cause physical pain or deny a reasonable humane existence to persons with disabilities. The bill was heard by the Joint Committee on Children, Families, and Persons with Disabilities. Lydia's testimony stated that people with disabilities deserve safe and humane treatment, intervention, and services options that respect the inherent human dignity, maximize autonomy, and minimize pain or suffering. An additional Council member provided oral testimony to the Committee in support of the bill. Council staff submitted testimony to the Joint Committee on Public Safety and Homeland Security on SB. 1313: An act relative to criminal justice training regarding autistic persons. The bill would require the Municipal Police Training Committee to establish within the recruit basic training curriculum a course for appropriate interactions with persons on the autism spectrum. SB 1313 and SB 1221 made progress in the 2017-2018 legislative sessions, as both bills are currently in Senate Ways and Means and awaiting further action. H 93, however, hit a bit of a roadblock when it was sent to study. The Council will continue its effort to educate lawmakers on the importance of the still active legislation at the beginning of FY19. With policymakers being educated on these key pieces of legislation, the grand total of people with developmental disabilities participating in Council supported activities in FY18 was 128. The Council also surveyed individuals with developmental disabilities who participated in Council supported activities during FY18. Respondents were asked whether they were satisfied with the activity they participated in and 21 of the 23 respondents indicated that they were satisfied with the Council's work on the activity. All data under this objective was found through attendance records from these trainings, events, and legislative hearings.

The Council also utilized social media platforms such as Facebook and Twitter to conduct safety awareness activities and inform the general public. Our projected output was 14 posts. This was exceeded by 200%. The Council's top viewed post reached 1490 people: National Association of County & City Health Officials' Health and Disability Program is currently accepting applications for its Disability Technical Assistance Program. This initiative supports local health departments (LHDs) in developing programs, products, and services that are inclusive and accessible for people with disabilities. The Council's social media efforts fostered a greater understanding of the safety issues impacting people with disabilities and provided additional resources to help them live safely in their communities.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Increased number of PWDD developing awareness and safety skills Increased number of people understand and can promote safety and rights Policymakers have an increased awareness of what people with developmental disabilities need to live safe and free from abuse in the community.	true

## 13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

While the Council succeeded in training PWDD in developing awareness and safety skills, in addition to promoting safety and rights of PWDD, there is still more work to be done toward further increasing those numbers and collecting additional follow-up data from participants in the remaining years of state plan implementation. MASS and the Council are developing strategies to improve in this area moving forward.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council could not report of any stories for this objective of culturally diverse people with developmental disabilities during this time due to the aforementioned barrier of data collection in compiling demographic information from individuals who participated in Council supported activities. Council membership reviewed and selected multiple pieces of legislation that were filed in 2017 relevant to the rights and safety objective 4.1. In 2018, a majority of those pieces of legislation were referred to the House and Senate Committee on Ways and Means, where they currently await further action. However, one policy priority was sent to “study” in 2018, HB 93: An Act regarding the use of aversive therapy. This bill will not progress any further in the legislature in 2018. This bill would effectively ban the use of aversive therapies in Massachusetts; however, due to the bill being sent to study, this will result in a negative impact on individuals with developmental disabilities in Massachusetts who are still subject to aversive therapy.

## Individual & Family Advocacy Performance Measure

### Description



## Exercising Rights

### Race/Ethnicity

Race/Ethnicity	#	%
White, alone	33	82.5
Black or African American alone	3	7.5
American Indian and Alaska Native alone	0	0
Hispanic/Latino	4	10
Asian alone	0	0
Native Hawaiian & Other Pacific Islander alone	0	0
Two or more races	0	0
Race unknown	0	0

### Gender

Gender	#	%
Female	28	70
Male	11	27.5

<b>Gender</b>	<b>#</b>	<b>%</b>
<b>Other</b>	1	2.5

Category

<b>Category</b>	<b>#</b>	<b>%</b>
<b>Individual with DD</b>	33	82.5
<b>Family Member</b>	7	17.5

Geographical

<b>Geographical</b>	<b>#</b>	<b>%</b>
<b>Urban</b>	0	
<b>Rural</b>	0	

I. Output Measures

Objective	Performance Measure : IFA 1.1 People with DD who participated in activities	Performance Measure : IFA 1.2 Family members who participated in activities
A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.*	74	40
A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.*	2	12
A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.*	128	2
Total # of Output Respondents	33	7

## II. Outcome Measures

Performance Measures	Percent (%)
IFA 2.1 Percent of people with DD who increased advocacy	94
IFA 2.2 Percent of family members who increased advocacy	100

Sub-Outcome Measures : The number (#) of people who are better able to say what they want/say what is important to them

Projects	# People with developmental disabilities	# Family Members
A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.*	0	0
A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.*	0	0
A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.*	0	0

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>Total # of Sub-Outcome Respondents</b>	0	0
<b>IFA 2.3 Percent of people better able to say what they need</b>	0	0

Sub-Outcome Measures : The number (#) of people who are participating in advocacy activities

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.*</b>	0	0
<b>A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.*</b>	0	0

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	0	0
<b>IFA 2.4 Percent of people participating in advocacy activities</b>	0	0

Sub-Outcome Measures : The number (#) of people who are on cross disability coalitions, policy boards, advisory boards, governing bodies and/or serving in leadership positions.

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.*</b>	0	0

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.*</b>	0	0
<b>A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	0	0
<b>IFA 2.5 Percent of people on cross disability coalitions</b>	0	0

**IFA 3 The percent of people satisfied with a project activity\***

92.5

**IFA 3.1 Percent of people with DD satisfied with activity\***

91.3

**IFA 3.2 Percent of family members satisfied with activity\***

100

## System Change Performance Measures

### Description

Exercising Rights



SC 1: Output Measures - The number of Council efforts to transform fragmented approaches into a coordinated and effective system that assures individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

Objective	SC 1.1 Number of policy/ procedures created/ changed	SC 1.2 Number of statutes/ regulations created/ changed	SC 1.3.1 Number of promising practices created	SC 1.3.2 Number of promising practices supported through Council activities	SC 1.3.3 Number of best practices created	SC 1.3.4 Number of best practices supported through Council activities	SC 1.3 The number of promising and/or best practices created and/or supported	SC 1.4 Number of people trained/ educated	SC 1.5 Number of Systems Change activities with other organizations
A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.	0	0	0	0	0	0	0	20	0

<b>Objective</b>	<b>SC 1.1 Number of policy/ procedures created/ changed</b>	<b>SC 1.2 Number of statutes/ regulations created/ changed</b>	<b>SC 1.3.1 Number of promising practices created</b>	<b>SC 1.3.2 Number of promising practices supported through Council activities</b>	<b>SC 1.3.3 Number of best practices created</b>	<b>SC 1.3.4 Number of best practices supported through Council activities</b>	<b>SC 1.3 The number of promising and/or best practices created and/or supported</b>	<b>SC 1.4 Number of people trained/ educated</b>	<b>SC 1.5 Number of Systems Change activities with other organizations</b>
<b>A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.</b>	0	0	0	0	0	0	0	0	0
<b>A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.</b>	0	0	0	0	0	0	0	0	0

Systems Change SC 2: Outcome Measures

Outcome Measures	Number(#)
SC 2.1 - Efforts that led to improvements *	0
SC 2.2 - Efforts that were implemented *	0

Sub-Outcome Measures

Objective	SC 2.1.1 Policy, procedure, statute, regulation improvements	SC 2.1.2 Policy, procedure, statute, regulation implemented	SC 2.1.3 Number of improved promising or best practices	SC 2.1.4 Number of implemented promising or best practices
A minimum of 500 people with developmental disabilities will have the opportunity to vote for the first time by September 30, 2021.	0	0	0	0

<b>Objective</b>	<b>SC 2.1.1 Policy, procedure, statute, regulation improvements</b>	<b>SC 2.1.2 Policy, procedure, statute, regulation implemented</b>	<b>SC 2.1.3 Number of improved promising or best practices</b>	<b>SC 2.1.4 Number of implemented promising or best practices</b>
<b>A minimum of 50 family members and people with developmental disabilities will pursue alternatives to full guardianship by September 30, 2021.</b>	0	0	0	0
<b>A minimum of 250 people with developmental disabilities will understand their rights and will be supported to live safely in the community by September 30, 2021.</b>	0	0	0	0

## Detailed Progress Report on Goals

Description

## Inclusive Communities

### Area Of Emphasis

Area of Emphasis	Planned for this goal	Areas addressed
Quality Assurance		
Education and Early Intervention		
Child Care		
Health		
Employment	true	true
Housing	true	true
Transportation		
Recreation		
Formal and Informal Community Supports	true	false

## Strategies

Strategies	Planned for this goal	Strategies Used
Outreach	true	true
Training	true	true
Technical Assistance		
Supporting and Educating Communities		
Interagency Collaboration and Coordination	true	true
Coordination with Related Councils, Committees and Programs	true	true
Barrier Elimination		
Systems Design and Redesign		
Coalition Development and Citizen Participation		
Informing Policymakers	true	true
Demonstration of New Approaches to Services and Support		
Other Activities		

### 3. Intermediaries/Collaborators

Collaborators	Planned for this goal	Actual
State Protection and Advocacy System		
University Center(s)	true	true
State DD agency	true	true
MA Advocates Standing Strong	true	true
Independent Living Centers	true	true
MA Rehabilitation Commission	true	true
Autism Housing Pathways	true	true

**Provide an overall cohesive description of (a) the extent to which progress is being made in achieving the intended outcomes of the Goal for the reporting year, (b) the extent to which each goal was or was not achieved for the reporting year, (c) where applicable, factors that impeded goal achievement for the reporting year, (c) needs that require substantive state plan amendment (goal only)**

The Council is making effective progress towards providing individuals and family members with information and guidance leading towards meaningful and inclusive lives in their community. The Council defines “meaningful lives” as living in the community and access to competitive, integrated employment. In addition, the Council continues to address policymakers on both the national and state level about barriers that inhibit the pursuance of these civil rights. The benchmarks set forth in year two of the goal are on track to being met. Various educational initiatives have taken place to address the shortfall in housing for people with disabilities through a grant with the Autism Housing Pathways. One hundred and thirty-three family members have participated in Housing related trainings designed to increase their knowledge on available

housing options. Regarding employment, the Council has been an expert subject matter contributor on the both National and State level through its' ongoing participation in the MA Partnership on Transition on to Employment, the Council on State Governments Stay-at-Work/ Return-to-Work program, and various Statewide Rehabilitation Council working groups. In addition, the Council continues to offer employment skill-development trainings to young adults through its' Independence College training. In FY 18, thirty-four people with DD/IDD have gained the skills needed to obtain competitive, integrated employment through their participation in Council supported activities. The Council will continue to build on the success in FY18, in addition to surveying FY18 participants on Council led trainings and workgroups.

**4 Year Overview : A description of how the Council will use and build from knowledge gained and progress made to move forward in the next state plan cycle.(This section only applies to the PPR submitted for the Federal Fiscal Year 2020, which will be due by January 1, 2021)**

**5 Year Overview : For the final PPR of this state plan cycle, provide an overall analysis of the outcomes achieved during the five year state plan cycle. The description should include the extent to which diverse stakeholders are satisfied with council activities that promote self-determination and community participation for individuals with disabilities and families, results of other types of information gathering such as focus groups, surveys, or other feedback or input methods with individuals with developmental disabilities and families and major accomplishments and factors impeding goal achievement (if applicable).(This section only applies to the PPR submitted for the Federal Fiscal Year 2021, which will be due by January 1, 2022)**

Objectives



1. A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.

1. **Goal:** Inclusive Communities

2. **State Plan Objective** Objective 2

3. **This Objective is**

Individual & Family Advocacy

4. **This Objective is**

Ongoing

5. **This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	No
b. Targeted disparity *	No
c. DD Network Collaboration *	No

	The Objective is
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

## 6. Stage of Implementation

Implementation

## 7. Provide an overall description of this effort

The Council addressed the high unemployment rate for people with developmental and intellectual disabilities in MA through a variety of statewide and Council-led initiatives. The Council conducted employment skills trainings through Independence College. Also, Council staff played leadership roles in national and statewide initiatives that are focused on increasing employment opportunities (Employment First Massachusetts, PIE/Mass Careers/Model Employer, CSG, MRC advisory groups). The Council educated policymakers about the gaps that exist in the availability of higher education opportunities for students with disabilities. In addition the Council continues to meet with the administration and other stakeholders on initiatives leading to the development of alternative methods for students with DD/IDD to obtain a high school diploma.

## 8. Outputs Achieved

Expected Outputs	Achieved
2 employment classes conducted through Independence College 25 students with developmental disabilities complete employment classes 4 statewide employment related committee meetings attended 200 policy makers educated about the gaps in the availability of higher education opportunities 20 social media posts on Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

Council staff attended 13 statewide employment related committee meetings in FY 18, and collaborated with the Employment Advocacy Group in an effort to increase the percentage of individuals with developmental disabilities who are employed in the state. The Commonwealth has established a 7% goal of employment for individuals with disabilities in the state of Massachusetts

in state procurement and contracting. The following goals were identified to expand the inclusion of and opportunities for individuals with disabilities: 1. Contract Anti-Discrimination Terms: to ensure that contractors are aware of their responsibility for adhering to existing laws that prohibit discrimination against individuals with disabilities; 2. Expand Inclusion of Disability-Owned Business Enterprise (DOBE): An executive order authorizes the Commonwealth's Supplier Diversity Program to include DOBE's; 3. Develop a Central Repository of Resources for Individuals with Disabilities: the SDO must provide assistance to the executive offices in determining the opportunities for contracting with businesses that hire persons with disabilities; 4. Due Diligence Review of Current and Best Practices: the SDO has turned to state legislative proposals and other relevant federal laws and regulations to develop a baseline of current practices by contractors and the general population; 5. Establishing Employment Percentage Goals: by FY2019, the SDO will set a utilization goal of 7% for the inclusion of qualified individuals with disabilities.

The Employment Advocacy Group also met with the Chief Human Resources Officer of the Commonwealth. The group, including many self-advocates, expressed concerns with the state's efforts to be a Model Employer. The chief admitted that the Human Resources Division is 'not doing enough' and that they need to implement more impactful policies that can lead to more individuals with disabilities finding employment. MDDC staff suggested that HRD look at current state agencies best practices at hiring people with disabilities and model their approach off of the practices that have been successful.

The Council participated in numerous meetings hosted by the Massachusetts Rehabilitation Commission (MRC) and the State Rehabilitation Council (SRC). The Council collaborated with the SRC's Business and Employment Opportunity Committee, the Unserved/Underserved Committee, and the State Plan Committee. The SRC is tasked with submitting recommendations to the MRC, and these meetings centered on discussions about MRC's efforts in delivering VR Services. In FY18 MRC ran into a budget shortfall, and federal regulations require an Order of Selection policy be implemented when the VR program does not have sufficient funds to serve all eligible consumers. It was decided that the MRC will implement Order of Selection in FY19. The MRC also consolidated career centers to help bridge the funding gap.

Council staff participated in the National Taskforce on Workforce Development for People with Disabilities, a partnership of the Council on State Governments and the U.S. Department of Labor's Office of Disability Employment Policy. The taskforce launched the State Exchange on Employment and Disability (SEED), a collaborative effort with state intermediary organizations, including the National Conference of State Legislatures. SEED's goal is to help states effectively address policy barriers that hinder the employment of people with disabilities. Through these partnerships, SEED supported CSG and DOL in providing a webinar and survey efforts to understand the needs of stakeholders. 143 people participated in the webinar and survey efforts. The Council also partnered with these organizations for Work Matters: Hiring and Retaining Workers with Disabilities, a full-day event which focused on employer practices and state policies that addressed the hiring, retention, and re-entry of people with disabilities in the workplace. More than 70 people were presenting, networking, educating, and representing policy or advocacy for people with disabilities at this event.

Council staff continues to take a leadership role as Committee Chair on the Massachusetts Partnership for Transition to Employment (MPTE) research and implementation grant. The MPTE is designed to improve employment outcomes for individuals with intellectual and developmental disabilities transitioning from school to adult life. MPTE is funded by a 5-year federal grant from the Administration on Intellectual and Developmental Disabilities. The Consortium will drive the policy and systems change work of the project. Membership consists of a broad range of organizations representing various constituencies that play key roles in transition and employment. Seven members of the Consortium serve as the MPTE Steering Committee, establishing and implementing the governance structure for the project, providing leadership, guidance and advice for all project activities, and ensuring that goals and objectives are carried out.

The full Consortium consists of the 7 Steering Committee members, and the following 14 additional organizations: Advocates for Autism MA Association of Developmental Disability Providers (AAPD), Administrators of Special Education, Boston Public

Schools, Disability Law Center, Executive Office of Health and Human Services Transition, Executive Office of Higher Education, Federation for Children with Special Needs, MA Advocates for Children, MA Commission for the Blind (VR), MA Down Syndrome Congress, MA Families Organizing for Change, Partners for Youth with Disabilities, Triangle Inc., WORK Inc. Additional members of the Consortium will be added, including representatives from a cross-section of school districts. During FY 18, Council staff has lead quarterly full consortium meetings to discuss research findings around employment outcomes for young adults with DD/IDD. A survey was developed and finalized by the subcommittee with the goal of having a clearer understanding of the self-advocate experience in an IEP team meeting, and how their employment goals were received by other members of the IEP professional team. The survey will be distributed in FY19 to self-advocate groups across the state.

The Council launched its Disability Employment Awareness month celebration by spotlighting 4 self-advocates who have gained competitive employment by utilizing the skills taught at the Council's Self-Advocacy Leadership Series and Independence College program. All 4 self-advocates were asked about their Council affiliation, current role at their job, and advice to other self-advocates who are actively seeking work. In addition, the spotlight also included their advice to employers. One spotlight a week was written and shared with the general public via email distribution and social media.

The Council provided funding to Massachusetts Advocates Standing Strong (MASS) to teach the Explore Prepare Act (EPA) class to students enrolled in the Council's Independence College program. This class focuses on skill develop for job readiness at the most basic level. The EPA Trainers are individuals with disabilities who utilize classroom lectures, videos and interactive activities to prep students on how to begin their job search. Three separate EPA classes were taught to three groups of Independent College classes. A total of 26 students completed the class. MASS applied \$7,500 of the \$60,000 Council grant to meet this objective.

The Council held a 3 week focus group to solicit feedback on a new employment series that is in development. 8 people and 4 supporters participated. The group engaged in 6 hours of activities over a 3 day period. Participants also did homework activities that highlighted the importance of building a portfolio and creating a personal network with updated contact information and creating a resume.

Council staff engaged the MA Department of Education to discuss HiSet preparation and alternative options to a traditional diploma for students with disabilities. The HiSET® exam is one of three tests U.S. states and territories use to measure high school equivalency skills. Massachusetts' does have a portfolio path for those students who are unable to successfully pass the Massachusetts Comprehensive Assessment (MCAS). The portfolio program has mostly been used with students with health care needs who are unable to participate in a traditional classroom/testing setting. It is used with students with high anxiety around test taking. The target audience has not been students with ID/DD. HiSet is not administered in a general education setting, rather, it is part of Continuing Education after a student completes/ages out of school.

The question remains whether this program can be utilized with ID/DD students. In FY 19, the Council will continue to work with students, parents, and the Department to find alternative solutions for students who are unable to pass the traditional MCAS.

The Council worked closely with legislators on four Higher Ed bills that, if passed, would lead to skill development for employment. SB698/HB634 - An Act creating higher education opportunities for students with intellectual disabilities, autism, and other developmental disabilities. A fact sheet was developed laying out the impact the bill has on student with ID/DD, in addition to Council testimony at the bill hearing. The Council reached out to 35 legislators on House Ways and Means, 16 legislators on Senate Ways and Means, and 18 members of the Joint Committee on Higher Ed. Both bills were reported favorably and currently reside in both HWM and SWM. In addition, the Council also educated SWM and HWM about the impact of SB 58/HB 2866: An Act providing equal access to evaluations for children with disabilities. The Council will continue its educational campaign about the impact of both higher education bills and a direct correlation to employment in FY19.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Increased number of PWDD develop employment related skills Increased number of PWDD are aware of post-secondary opportunities Policymakers have an increased awareness of the importance of post-secondary education opportunities	true

## 13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

The Council is making overall effective progress in achieving the outcomes set forth under the objective. Council staff attended 13 statewide employment related committee meetings in FY 18 (MPTE, CSG annual conference, Employment Coalition quarterly meetings, MOD's annual summit). The Council collaborated with the Employment Advocacy Group on a quarterly basis in an effort to increase the percentage of individuals with developmental disabilities who are employed in the state. The Council provided expertise in numerous meetings hosted by the Massachusetts Rehabilitation Commission (MRC) and the State Rehabilitation Council (SRC). The Council is a subcommittee member of the SRC's Business and Employment Opportunity Committee , the Unserved/Underserved Committee, and the State Plan Committee. The SRC is tasked with submitting recommendations to the MRC, and these meetings centered on discussions about MRC's efforts in delivering VR Services. The Council funded 3 Employment Trainings through its Independence College program. A total of 26 students with ID/DD completed the Explore, Prepare, Act training learning specifically about job preparation skills. The Council continues to use social media (Facebook, Twitter) to inform people with DD/IDD about employment skill development, career fairs, and other events going on across the state. The Council educated policymakers about the gaps that exist in the availability of higher education opportunities for students with DD. Sixty-nine policy makers were educated around the importance of higher education



as it related to achieving employment. The Council continues to work with students, parents, and the Department of Education to develop alternative methods for students with DD/IDD to obtain a high school diploma that are unable to pass the Massachusetts Comprehensive Assessment test (MCAS).

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council worked closely with legislators to bring awareness on the need of policy changes that would allow students with disabilities to access the higher education curriculum. SB698/HB634 - An Act creating higher education opportunities for students with intellectual disabilities, autism, and other developmental disabilities, would lead to skill development for employment. This was a key policy priority for the Council given the impact/improved outcomes (and cost-effective) so important to move forward and enact as expeditiously as possible. Both bills were reported favorably and currently reside in both HWM and SWM. More work is being done as the bills enter the informal session. The Council worked with culturally diverse populations through the Self-Advocacy Leadership Series (SALS), Realizing Independence and Self-Empowerment (RISE), the Autism Housing Pathways, and other council funded initiatives. The populations impacted are reported in other state plan objectives throughout the PPR.

2. A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.

1. **Goal:** Inclusive Communities

2. **State Plan Objective** Objective 1

3. **This Objective is**

Individual & Family Advocacy

4. **This Objective is**

Ongoing

5. **This Objective is**

	The Objective is
a. Fulfilling a Self-Advocacy DD Requirement *	No
b. Targeted disparity *	No
c. DD Network Collaboration *	No

	The Objective is
d. A demonstration project of New Approaches to Services and Supports *	No
e. A demonstration of projects or activities *	No

## 6. Stage of Implementation

Implementation

## 7. Provide an overall description of this effort

Based on the Council's analysis of housing availability for people with DD/IDD, the Council determined that increased awareness and education about housing options was lacking. In the prior fiscal year, the Council had begun addressing this lack of information sharing by focusing on educating applicable stakeholders through trainings and a robust, targeted social media campaign. FY 18 continued our work on educating individuals and families about housing options that were most suitable to their individual needs.

## 8. Outputs Achieved

Expected Outputs	Achieved
1 initiative supported 1 grant implemented to educate families about housing options 12 individuals educated 26 family members educated 25 PWDD and family members engaged in advocacy around housing 200 policymakers educated about access to services and supports 10 social media posts through Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

In 2017 the Council sparked a conversation among Autism Housing Pathways, and officials with the Massachusetts Autism Commission, the Community Economic Development Assistance Corporation, and the Massachusetts Rehabilitation Commission. The discussion led to the language in the Housing Bond Bill. The Bill allows families to borrow up to \$50,000 for the purposes of creating an accessory unit. In FY 18, MA Governor In FY18, the governor signed the Housing Bond Bill, which will allow families to borrow up to \$50,000 for the purposes of creating an accessory unit. This aspect of the bond bill grew out of work of the Council and its' partners mentioned above.

The Council's additional housing activities were implemented through a \$20,000 training grant awarded to Autism Housing Pathways (AHP.) The purpose of the training grant is to help individuals with developmental disabilities and their families to develop a housing strategy, take concrete steps to implement it, understand how to maintain tenancy, and participate in advocating for their housing needs. Three distinct cohorts were involved in three activities: Individuals with developmental disabilities and their families; Family members of students with developmental disabilities who attend Boston Public Schools, and; Individuals with autism able to read at the 8th grade reading level.

20 family members and 12 individuals participated in daylong workshops implemented by the Autism Housing Pathways (AHP) and/or completed the AHP Housing Workbooks. The individuals and families received housing workbooks to complete with their family members prior to engaging in person-centered planning. Three families and a self-advocate (accompanied by a teacher) participated in a four hour workshop at English High School in Boston, including instruction in how to apply for housing from the Boston Housing Authority, state elderly housing, the Autism Housing voucher program, and the Section 8 Housing Choice Voucher Program (via the DHCD regional non-profit and Centralized Waiting lists). The teacher who accompanied the self-advocate wrote, "There are (sic) a lot of information to digest, I would love to encourage teachers/family members to participate in this training." All the families that completed the Boston workshop reported strongly agreeing they are better able to advocate for their family member. In addition, the teacher who accompanied the self-advocate answered this question (the self-advocate had to leave for work before the end of the day), and also strongly agreed. Interest has been expressed by a major human services agency in having this workshop presented in Lynn to families who do not speak English as their first language. Two of the families completed Section 8 applications during the training. for the Boston workshop were translated into six languages: Arabic, Chinese, Haitian Creole, Portuguese, Spanish, and Vietnamese. These materials are now available for public use on the Autism Housing Pathways website and has been shared via the Council's social media campaign. In addition to in person trainings, the AHP grant developed "A Place of My Own" online course that was published on Teachable, at: <http://ahphousing.teachable.com/>. It is available for free. The course comprises seven modules, with a total of 30 separate lessons. Modules are: Getting ready to rent; The rental process; Tenant responsibilities, including taking care of your place; Landlord responsibilities; Landlord/tenant disputes; Breaking the lease; and Tenant rights. The course incorporates material from NeighborWorks America's course on counseling clients seeking rental housing with material that dives deeper into the needs of renters with

developmental disabilities. NeighborWorks America is a congressionally chartered non-profit that is the leading trainer of housing counselors. It is estimated it will take about 15 hours to complete the course. During the final reporting period for FY18, AHP reached out to participants that took part in AHP trainings to report on their experiences participating in the grant. 11 of the 12 families that originally signed up completed all grant activities, and 9 families completed post-workshop surveys to assess what steps they had taken since completing the daylong workshop. Additionally, eight families and three individuals completed the Massachusetts Developmental Disabilities Council follow-up questionnaires. Significantly, all individuals who completed the trainings are now on at least one portable Section 8 waiting list. Additionally, three have applied for project-based Section 8, one has applied for state elderly/disabled housing, and two have applied for other public housing. Other outcomes are that two applied for services through the Department of Developmental Services, one applied for services through the Massachusetts Rehabilitation Commission, six are participating in daily living skills training, and one family has completed a special needs trust. Of those who completed follow up surveys, 88% of family members are white and one is Asian; 67% of individuals with disabilities are white, and 33% are Asian. Everyone who completed a survey indicated they were satisfied with the activity.

Additionally, work on the online course on being a tenant (Objective 2) was completed. 20 students enrolled, and one has completed the course and provided feedback. It seems likely the course will be most successfully accessed by students working in a structured setting, such as a transition program at the high school or college level, where they can receive support. We are in conversations with two such programs, and plan to reach out to more.

The Council worked in partnership with the Arc of Massachusetts and the Autism Housing Pathways through the development of policy strategies that would have the greatest impact on people with DD/IDD in Massachusetts. A key joint policy priority related to housing in FY 18 was a bill filed by Senator Barbara L'Italien: An Act relative to accessory dwelling units. The legislation is relative to the development and preservation of affordable housing for persons with disabilities and the elderly; is designed to encourage creation of long-term housing stock for people with disabilities and seniors in the form of 2 bedroom accessory apartments. Council member

delivered testimony on both of the Housing related bills in FY17. In collaboration with the Council, AHP, and The Arc of Massachusetts, Autism Housing Pathways (AHP) organized families to contact the Senate Committee on Rules, and later, the offices of the speaker of the house and the governor to support S. 2132 (formerly S. 729). Over 1,000 recipients were contacted by AHP's call to action sent via MailChimp, and it was opened by 263 recipients. More were reached by a call to action sent by The Arc. 41 additional families reported engaging in outreach this reporting period; reports were received via email and Facebook.

Despite intensive educational outreach by the Council and 76 additional families educated through the Council's AHP grant who also reached out to the legislature and the governor's office, the accessory apartment zoning bill failed to advance as written from the Senate Committee on Rules. Thanks to the efforts of the families, key language was lifted from the bill and inserted into the Senate's version of the governor's housing bill. However in the end, that bill was not brought to the floor for a vote. The Council, AHP and the Arc of Massachusetts to refile the bill next session with new and/or additional sponsors. The Council educated people with disabilities and families utilizing social media. Our projected output was 10 posts. This was exceeded by 108% with 12 posts. The Council's top viewed post reached 3860 people: Mass Access is a free program that matches people with disabilities with vacant, accessible housing. Any person who has a disability, family member, or advocate can obtain housing information, regardless of age, income or type of disability. To learn more information about the Massachusetts Accessible Housing Registry, follow the link below: <http://www.mass.gov/eohhs/consumer/disability-services/housing-disability/massaccess.html>

## **12. Expected Outcomes Achieved**

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Expected Outcomes	Achieved
<p><b>Individuals and family members have Increased knowledge of housing options. Increased opportunities for individuals and family members to pursue affordable, integrated housing options. Policymakers have an increased awareness of best practices in housing.</b></p>	<p>true</p>

**13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.**

The Council is making effective progress in educating individuals and family members about affordable, integrated housing options. The Council grant awarded to the Autism Housing Pathways (AHP) was used in part to facilitate a day-long workshop that educated 12 individuals and 20 family members. The grantee also developed an online course on the responsibilities of being a tenant, and was completed by 20 transitioned aged students with DD/IDD. In addition to in-person trainings, the AHP grant developed "A Place of My Own" online course that was published. The Council exceeded its' social media educational goal by 108%. The campaign focused on educating people with DD/IDD and their families about affordable, accessible housing for people with disabilities and the Massachusetts housing laws. The most successful post was viewed by over 1500 people. The Council continued to educate legislators about housing related bills voted on as top priority by our membership. Meetings were held with the Senate Committee on Rules about a bill filed relative to the development and preservation of affordable housing for persons with disabilities and the elderly; is designed to encourage creation of long-term housing stock for people with disabilities and seniors in the form of 2 bedroom accessory apartments.



**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council awarded a grant to the Autism Housing Pathways to specifically reach out to underserved communities. The grant paid for training materials for culturally diverse, underserved communities on how to apply for housing from the Boston Housing Authority, state elderly housing, the Autism Housing voucher program, and the Section 8 Housing Choice Voucher Program. The materials were were translated into six languages: Arabic, Chinese, Haitian Creole, Portuguese, Spanish, and Vietnamese.

## Individual & Family Advocacy Performance Measure

### Description

Inclusive Communities

Race/Ethnicity

<b>Race/Ethnicity</b>	<b>#</b>	<b>%</b>
<b>White, alone</b>	35	62.5
<b>Black or African American alone</b>	14	25
<b>American Indian and Alaska Native alone</b>	0	0
<b>Hispanic/Latino</b>	4	7.14
<b>Asian alone</b>	3	5.36
<b>Native Hawaiian &amp; Other Pacific Islander alone</b>	0	0
<b>Two or more races</b>	0	0
<b>Race unknown</b>	0	0

Gender

<b>Gender</b>	<b>#</b>	<b>%</b>
<b>Female</b>	32	64
<b>Male</b>	18	36
<b>Other</b>	0	0

Category

Category	#	%
Individual with DD	54	32.73
Family Member	111	67.27

Geographical

Geographical	#	%
Urban	41	73.21
Rural	15	26.79

I. Output Measures

Objective	Performance Measure : IFA 1.1 People with DD who participated in activities	Performance Measure : IFA 1.2 Family members who participated in activities
A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.*	37	4

<b>Objective</b>	<b>Performance Measure : IFA 1.1 People with DD who participated in activities</b>	<b>Performance Measure : IFA 1.2 Family members who participated in activities</b>
<b>A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.*</b>	17	107
<b>Total # of Output Respondents</b>	51	106

## II. Outcome Measures

<b>Performance Measures</b>	<b>Percent (%)</b>
<b>IFA 2.1 Percent of people with DD who increased advocacy</b>	80
<b>IFA 2.2 Percent of family members who increased advocacy</b>	98.2

Sub-Outcome Measures : The number (#) of people who are better able to say what they want/say what is important to them

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.*</b>	34	0
<b>A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.*</b>	16	0
<b>Total # of Sub-Outcome Respondents</b>	50	102
<b>IFA 2.3 Percent of people better able to say what they need</b>	98	96

Sub-Outcome Measures : The number (#) of people who are participating in advocacy activities

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.*</b>	0	0
<b>A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	0	0
<b>IFA 2.4 Percent of people participating in advocacy activities</b>	0	0

Sub-Outcome Measures : The number (#) of people who are on cross disability coalitions, policy boards, advisory boards, governing bodies and/or serving in leadership positions.

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.*</b>	0	0
<b>A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	0	0
<b>IFA 2.5 Percent of people on cross disability coalitions</b>	0	0

**IFA 3 The percent of people satisfied with a project activity\***

97.7

**IFA 3.1 Percent of people with DD satisfied with activity\***

95.7

**IFA 3.2 Percent of family members satisfied with activity\***

100

## System Change Performance Measures

### Description

Inclusive Communities



SC 1: Output Measures - The number of Council efforts to transform fragmented approaches into a coordinated and effective system that assures individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

Objective	SC 1.1 Number of policy/ procedures created/ changed	SC 1.2 Number of statutes/ regulations created/ changed	SC 1.3.1 Number of promising practices created	SC 1.3.2 Number of promising practices supported through Council activities	SC 1.3.3 Number of best practices created	SC 1.3.4 Number of best practices supported through Council activities	SC 1.3 The number of promising and/or best practices created and/or supported	SC 1.4 Number of people trained/ educated	SC 1.5 Number of Systems Change activities with other organizations
A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.	0	0	0	0	0	0	0	0	0

Objective	SC 1.1 Number of policy/ procedures created/ changed	SC 1.2 Number of statutes/ regulations created/ changed	SC 1.3.1 Number of promising practices created	SC 1.3.2 Number of promising practices supported through Council activities	SC 1.3.3 Number of best practices created	SC 1.3.4 Number of best practices supported through Council activities	SC 1.3 The number of promising and/or best practices created and/or supported	SC 1.4 Number of people trained/ educated	SC 1.5 Number of Systems Change activities with other organizations
A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.	0	1	2	1	0	0	0	0	2

Systems Change SC 2: Outcome Measures

Outcome Measures	Number(#)
SC 2.1 - Efforts that led to improvements *	2
SC 2.2 - Efforts that were implemented *	4

Sub-Outcome Measures

Objective	SC 2.1.1 Policy, procedure, statute, regulation improvements	SC 2.1.2 Policy, procedure, statute, regulation implemented	SC 2.1.3 Number of improved promising or best practices	SC 2.1.4 Number of implemented promising or best practices
<b>A minimum of 100 people with developmental disabilities will develop the skills needed to obtain competitive, integrated employment by September 30, 2021.</b>	0	0	0	0
<b>A minimum of 50 people with developmental disabilities and their families will have access to appropriate supports to pursue affordable, integrated housing options by September 30, 2021.</b>	0	2	2	2

# Detailed Progress Report on Goals

Description

Supporting Families

Area Of Emphasis

Area of Emphasis	Planned for this goal	Areas addressed
Quality Assurance	true	true
Education and Early Intervention		true
Child Care		
Health	true	true
Employment		
Housing		
Transportation	true	
Recreation	true	false
Formal and Informal Community Supports	true	true

## Strategies

Strategies	Planned for this goal	Strategies Used
Outreach	true	true
Training	true	true
Technical Assistance		true
Supporting and Educating Communities	true	true
Interagency Collaboration and Coordination		true
Coordination with Related Councils, Committees and Programs		
Barrier Elimination	true	false
Systems Design and Redesign		false
Coalition Development and Citizen Participation	true	true
Informing Policymakers	true	true
Demonstration of New Approaches to Services and Support		
Other Activities		

### 3. Intermediaries/Collaborators

Collaborators	Planned for this goal	Actual
State Protection and Advocacy System		true
University Center(s)		true
State DD agency	true	false
MA Lifespan Respite Coalition	true	false
MA Sibling Support Network	true	false
Autism Insurance resource Center	true	true
Supporting Families Coalition	true	true
Early Intervention Family Support Initiative	true	true
Horace Mann Educational Associates	true	true

**Provide an overall cohesive description of (a) the extent to which progress is being made in achieving the intended outcomes of the Goal for the reporting year, (b) the extent to which each goal was or was not achieved for the reporting year, (c) where applicable, factors that impeded goal achievement for the reporting year, (c) needs that require substantive state plan amendment (goal only)**

The Council achieved its intended outcomes under the Supporting Families goal for FFY2018. The accomplishments were made in collaboration with the Council's subgrantees, disability agencies, state agencies, family members and other stakeholders. Parents and other family members of people with disabilities increased their advocacy and their knowledge about family support. Over 200 policymakers in State

government were educated about the importance and benefits of providing family supports and services. Overall, family members increased knowledge and access to generic community resources. Families from underserved communities, including native speakers of Spanish, Vietnamese and Arabic, increased their knowledge and access to health insurance for Autistic family members.

**4 Year Overview : A description of how the Council will use and build from knowledge gained and progress made to move forward in the next state plan cycle.(This section only applies to the PPR submitted for the Federal Fiscal Year 2020, which will be due by January 1, 2021)**

**5 Year Overview : For the final PPR of this state plan cycle, provide an overall analysis of the outcomes achieved during the five year state plan cycle. The description should include the extent to which diverse stakeholders are satisfied with council activities that promote self-determination and community participation for individuals with disabilities and families, results of other types of information gathering such as focus groups, surveys, or other feedback or input methods with individuals with developmental disabilities and families and major accomplishments and factors impeding goal achievement (if applicable).(This section only applies to the PPR submitted for the Federal Fiscal Year 2021, which will be due by January 1, 2022)**

#### Objectives

1. A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.

**1. Goal:** Supporting Families

**2. State Plan Objective** Objective 2

**3. This Objective is**

Individual & Family Advocacy

**4. This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
<b>a. Fulfilling a Self-Advocacy DD Requirement *</b>	No
<b>b. Targeted disparity *</b>	Yes
<b>c. DD Network Collaboration *</b>	Yes
<b>d. A demonstration project of New Approaches to Services and Supports *</b>	No



	The Objective is
e. A demonstration of projects or activities *	No

## 6. Stage of Implementation

Implementation

### 7. Provide an overall description of this effort

The Council partnered with disability-focused organizations and awarded grants to organizations and family members of individuals with developmental disabilities to increase the number of families pursuing training and helpful resources about individualized family supports. The primary strategies initiated to achieve this objective were to educate underserved families from minority communities about MassHealth and Autism Insurance, educate low-income families about disability and generic community resources, provide funding for family members to attend training specific to their family members' individual needs and use networking and social media strategies to connect families to resources. Outreach and planning for the training activities began during the last quarter of FFY 2017.

Family members of individuals with developmental disabilities learned about a variety of supports and benefits available to them by attending trainings and webinars on health insurance, attending workshops on family supports and public benefits, and attending training specific to their own individualized needs through the Council Empowerment Funds program. The Council shared training opportunities, events and other information on social media with its followers on Facebook and Twitter throughout the year.

#### 8. Outputs Achieved

Expected Outputs	Achieved
1 grant implmented to educate underserved culturally diverse family members about Autism insurance and MassHealth 1 grant implemented to support families to pursue community resources available to support them and their family members with developmental disabilities. 80 families educated about pursuing available community resources 140 family members from minority communities educated about Autism and MassHealth 12 social media posts on Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

The Autism Insurance Resource Center (AIRC), a department within the University Center for Excellence in Developmental Disabilities (UCEDD) E.K. Shriver Center, collaborated with the Council to conduct health insurance training to linguistically underserved family members. With \$20,000 in Council grant funds and an additional \$2,000 nonfederal match, the AIRC conducted five trainings and three webinars that educated at least 82 people in Massachusetts. The exact number of webinar viewers is unknown. The project's purpose was to educate underserved families from linguistic and cultural minorities about autism treatments and services available through MassHealth and private insurance. Project goals were to reduce barriers, mitigate challenges, and provide resources so these families could access the benefits available to them. Project methodology focused on developing presentations and materials in Spanish, Vietnamese, and Arabic, and delivering trainings through webinars and live presentations in the community. AIRC implemented this by engaging Community Partners in each of these communities. For the Vietnamese and Arabic Communities, liaisons were consultants to the project team, and received a stipend for their services. For the Spanish-speaking community, AIRC partnered with various community organizations throughout the State in order to reach diverse populations.

Presentations were scheduled and publicized with the help of the consultants and liaisons. For the Arabic Community, the presentation was held in a mosque, at a time that was adjacent to prayer services. The Vietnamese presentation was held at a Community Health Center where many families regularly attend a support group. Presentations in Spanish were held at different locations including several schools that have special classrooms for Spanish speaking children with autism. A major accomplishment was to raise awareness in these communities of the coverage available under recent legislation, and provide resources for helping families pursue access. In addition, attendees learned about AIRC's services and ability to assist families with specific questions and issues. Attendees from each presentation and webinars followed up on issues ranging from request for assistance, locating treatment providers, resolution of enrollment problems and eligibility, and advice on educational advocacy.

Attendees responded favorably in their evaluations, reporting increased knowledge about insurance gained from their training. 70 family members participated in Council supported activities designed to increase their knowledge of how to take part in decisions that affect their families, the lives of others, and/or systems. Forty-nine people reported that they are better able to say what they want or say what services and supports they want or say what is important to them. Fifty one family members were satisfied with this project activity. Twelve professionals were trained or educated through Council system change initiatives. Through the AIRC grant, one promising practice was created and implemented. This project is in the implementation phase of systems change.

Horace Mann Educational Associates' (HMEA's) Autism Resource Central partnered with the Council to train low-income families in Central Massachusetts about community and government resources available to support them and their family members with developmental disabilities. The Council contributed \$4623 in grant funds and HMEA provided \$1,000 in matching funds in FFY 2018. In-kind donations include interpreting and workshop space provided by community health centers, early intervention centers, and other local organizations. 81 parents received training on how to access public supports available to them, including families who speak Portuguese and Spanish. Six workshops were held in community centers and in Worcester and surrounding communities to allow easy access for local residents. Instruction included information about services available from the Department of Developmental Services (DDS), Supplemental Security Income (SSI), MassHealth and its CommonHealth Premium

Assistance Program, ARICA (Massachusetts Autism Insurance Law), Personal Care Attendant programs, Kayleigh Mulligan program, Child Behavioral Health Initiative, the Council's Empowerment Funds, MA Rehabilitation Commission Home Modification program, Supplemental Nutrition Assistance Program benefits and fuel assistance programs. Information about respite services in the area was discussed and on-site respite care allowed parents to focus on learning without concern about their children. Breaks allowed time for networking with other families to create supportive connections. Participants were offered assistance to complete applications for appropriate programs and services.

Subsequent to the training, HMEA's Autism Resource Central enrolled 25 families in its program to gain access to the supports, educational programs and activities that the Center offers. 12 families sought follow-up assistance and were connected with the Disability Law Center, Parent Professional Advocacy League for children's mental health, Massachusetts Advocates for Children, Community Legal Aid, Central Mass Housing Alliance, the AIRC and Social Security Administration. They were assisted with applications for MassHealth and DDS, reinstating Mass Health and appealing an SSI ruling. Of 10 follow up surveys submitted, 9 people are better able to say what they want or what is important to them and are participating in advocacy activities. Ten family members returned surveys stating they increased their advocacy and are satisfied with this project activity, with several commenting that the training was excellent and important to continue.

The Council Empowerment Funds (CEF) provide support to individuals with developmental disabilities and family members to attend training and learn about resources to improve their quality of life. In FFY18, 26 family members were supported with \$5,566 to attend 12 different trainings that the participants chose based on their individualized needs. In a follow-up survey one parent wrote, "Three short months after her second birthday, my daughter was diagnosed with Autism. Her struggles with communication and transitions were becoming more difficult by the day, and I could see the divide widening between her and her peers. In attending this conference, I had the opportunity to network with other parents and hear their stories - their struggles and their victories. The vendor fair demonstrated to me how many resources were available to our family, even though we are located on our little island 30 miles out to sea. Being able to hear from the different state office representatives made me so proud to be from Massachusetts, and the keynote speakers were inspiring. I left the conference armed with knowledge and confidence on how to

make the next steps to transition my daughter to public preschool (and navigate the dreaded IEP process). I'm grateful to the Massachusetts Developmental Disabilities Council and the CEF for the opportunity to attend. Living in a rural area makes things a little bit harder and more expensive to attend, and as a single parent this would not have been financially viable otherwise."

The Council utilized networking and social media strategies via Facebook and Twitter to connect families to resources. The Council exceeded its FY18 target goal of 12 posts with 24 posts. The most popular announcement was viewed 1403 times. Information about generic community resources is often shared on the MDDC's Facebook page and via Twitter. In addition, HMEA and AIRC regularly shared information about their trainings on social media.

There were several challenges under this objective. Trainings scheduled in March had to be rescheduled and rescheduled again due to major snowstorms that shut down schools and businesses across the state. Many training sessions included multiple registrants who canceled without notice. Four family support trainings had to be canceled and/or rescheduled because of the weather and low/no turnout. AIRC encountered several distinct challenges in providing training to the three multilingual communities. In the Arabic Community, different segments (Iranians, Saudi Arabians, Syrians, Pakistanis), don't typically come together for events. AIRC mitigated this by broadly publicizing the presentation through different channels in each community. It was a diverse population, and attendance was a little lower than anticipated. In the Spanish-speaking community, there were concerns from families that pursuing coverage and/or advocating could jeopardize immigration status. While immigration concerns weren't directly raised in the other communities, this is a major concern that may discourage families from seeking assistance.

The Council evaluates grants through quarterly reports and ongoing communication with sub-grantees through meetings, emails and phone calls. Grantees and Council partners collect data using a combination of surveys and evaluation tools. Grantees enter narrative updates and data into the DD Suite, the Council's data and project management system. Data collection includes distributing MDDC Participant Surveys to collect follow up data from project participants who have developmental disabilities or are family members. For Council Empowerment Funding, recipients are reimbursed for expenses after completing an MDDC Participant Survey. There is low return on follow-up surveys, so overall project impact is more profound than the data suggests.

AIRC noted that actual numbers for performance indicators are higher, based on feedback from its Community Liaisons. This is supported by follow-up requests from some attendees for individual technical assistance, as well as referrals of families to its Center from other attendees.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Family members have Increased knowledge about system support networks and availability. Family members from underserved communities have increased knowledge about and access to Autism insurance and MassHealth. Family members have increased knowledge and access to generic community resources.	true

## 13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.

Substantial progress was made toward achieving outcomes for the overall objective. The Council met the three outcomes identified above for FFY 2018. Recognizing the continued and tremendous need of families, the Council and its partners will continue their work under this objective in FFY 2019.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

After attending HMEA's family support workshops, HMEA staff had several follow up conversations with two Spanish-speaking families which resulted in their addressing issues with Mass Health and submitting applications for services with the Department of Developmental Services (DDS.)

AIRC successfully helped one Arabic-speaking attendee post-presentation obtain full MassHealth benefits for his three children with disabilities (two with autism). He was previously unsuccessful due to a language barrier. One of the attendees at the presentation was a man from Pakistan, attending on behalf of a friend who has two children with autism. He brought information back to his friend, who subsequently reached out for assistance on accessing insurance-related services, as well as advice on educational advocacy.

One Vietnamese family's MassHealth had been terminated based on incorrect information. The family brought the documentation to the presentation. AIRC worked with its contacts and were successful in getting the family's Premium Assistance reinstated, along with retroactive payments. This benefit



of several hundred dollars each month now helps them obtain additional services and assistance for their child. Another Vietnamese parent received a letter saying that their coverage was terminated because their son no longer lived in Massachusetts (which was wrong). Unable to resolve this after many attempts, she reached out to AIRC, which was able to get the data corrected and coverage reinstated.

Several Spanish-speaking trainees followed up for individual assistance with insurance questions and help accessing therapy, especially with locating providers. In addition, as a result of AIRC's general outreach, requests to the Center for technical assistance from Spanish-speaking families dramatically increased. One family was very reluctant to seek assistance due to fears that their immigration status would be affected. Their landlord worked with AIRC on their behalf for several weeks to successfully resolve their issues. The child is now receiving Applied Behavioral Analysis therapy and is back on track learning.

AIRC's Community Liaison for Arabic speaking families, a Developmental Behavioral Pediatrician from Saudi Arabia, used the information from the presentation to help her patients while she completed her Fellowship in Massachusetts. She is bringing this knowledge and experience back to Saudi Arabia with her, where she hopes to apply it to work on systemic change in her country.

**2.** A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.

**1. Goal:** Supporting Families

**2. State Plan Objective** Objective 1

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**3. This Objective is**

Individual & Family Advocacy

**4. This Objective is**

Ongoing

**5. This Objective is**

	The Objective is
<b>a. Fulfilling a Self-Advocacy DD Requirement *</b>	No
<b>b. Targeted disparity *</b>	No
<b>c. DD Network Collaboration *</b>	No
<b>d. A demonstration project of New Approaches to Services and Supports *</b>	No
<b>e. A demonstration of projects or activities *</b>	No

## **6. Stage of Implementation**

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Implementation

### **7. Provide an overall description of this effort**

The Council collaborated with advocacy and interagency coalitions to address the activities specified under this State Plan Objective. During Federal Fiscal Year (FFY) 2018 new activities under this objective include raising awareness about Fetal Alcohol Syndrome and pay rates for in-home skilled nursing staff to care for medically fragile children. The Council partnered with disability and advocacy organizations with the common goal of improving individualized family supports across the Commonwealth of Massachusetts. The Council continued its collaboration from FFY 2017 with The Arc of Massachusetts, Supporting Families Coalition and Department of Public Health Interagency Coordinating Council. New partnerships were formed with the Institute for Health and Recovery and the Massachusetts Pediatric Home Nursing Campaign. Collective activities focused on improving family supports within the state human service system, conducting awareness and education activities on family supports, sharing information about family support on social media, and educating policymakers about the need for and benefits of providing individualized family support services.

## 8. Outputs Achieved

Expected Outputs	Achieved
2 initiatives to enhance opportunities to increase access to family supports 3 Council staff and Council members participating in initiatives 25 families participating in initiatives 1 policy advocated for that will improve support to families. 200 policy makers educated about affordable, independent evaluations 4 legislative networking events 12 social media posts on Twitter and Facebook	true

**10. The report should include the following: (a) A narrative progress report that cohesively describes the activities that were implemented toward achieving the objective, including how the identified strategy was used, how the activity was implemented, challenges to achieving the objective and unexpected benefits.(b) For system change activities, include a description of the stage of implementation (planning, initiation, implementation, outcome/fully integrated) of the system change initiative. (c) All narratives must describe what numbers make up the performance measures number for the activities being reported in the narrative.(d) A summary of evaluation activities to monitor progress and impact of council supported activities for the objective; data collected during the year, data sources, and data collection methods; (logic model and evaluation plan may be attached to the report).**

The Council partnered with the Supporting Families and MA 21 Coalitions, in FY18. The Supporting Families Coalition's goal is to educate policymakers about the importance and cost effectiveness of providing family support resources to families of individuals with developmental disabilities eligible for services in the Department of Developmental Services (DDS.) The Coalition raises

awareness about the challenges facing families caring for their loved ones with developmental disabilities at home. Members include representatives from the Council, The Arc of Massachusetts, Advocates for Autism in Massachusetts, Mass. Families Organizing for Change, and other advocates, self-advocates, and family members. The Supporting Families meetings focused around educating legislators on the importance of family support programs in the state budget, specifically through a flyer campaign in November (Caregiver Appreciation Month), and the the “This is My Life” campaign. Family members and individuals with ID/DD stressed the programs important to them to their legislators. The education of lawmakers also included a Story Telling Webinar held prior to Supporting Families Day at the State House. Seventeen family members attended the webinar in November 2017. Supporting Families Day was held, where an additional 34 family members had the chance to hear from State Representative Linda Dean Campbell about the importance of sharing their personal story with legislators, bringing the cumulative number of family members participating in these activities to 51 during FY18. Family members then met with their legislators throughout the State House, with literature about Supporting Families' priorities and candy-hearts for legislators (on February 13). The focus was also an MDDC policy priority, a bill which would establish a registry of caretakers found to have substantiated abuse against persons with ID/DD. MDDC Council members provided testimony and worked with legislators in amending the bill in the committee, which led to the bill being passed by the Senate in late July. The bill moved to the House where no action was taken to pass it by the end of the legislative session. The bill is being re-filed in the new legislative cycle beginning January, 2019. A family support FAQ document was distributed and discussed as well with the intention of providing it for evaluations at provider agencies. It was distributed to DDS Family Support Directors throughout the state, fully integrating this systems change initiative.

The MA21 Coalition’s meetings focused on the goal of conceptualizing what a comprehensive disability policy can and should look like. MA 21 addressed issues that have been raised by families. Specifically, families are frustrated and need to know what services are available and how to utilize them. In addition, individuals want control of their lives and to decide how their services/ supports are applied to their individual needs. Self-determination should be promoted regardless of the level of need an individual has. Policymaker education from MA21 overlapped with many of the same Supporting Families initiatives. The Council assisted

MA21 in providing input on a Self-Directed Individual Budget document that is still in the implementation stages. The document was designed to help individuals (and their family or supported decision-making team) identify and advocate for a budget that adequately funds the person's self-directed services.

The Council serves as a standing member of the Department of Public Health (DPH) statewide Interagency Coordinating Council (ICC) which advises and assists the DPH in planning, development and implementation of Early Intervention services. The ICC assists the DPH through active collaboration and engaged participation of members in order to optimize and sustain a comprehensive birth to three system, striving for a community based system of care that maximizes opportunities for all children and families. The ICC is comprised of seven family members representing all regions of Massachusetts, and professionals and providers representing state agencies, higher education, special education, the Legislature, medical profession and early childhood service providers. Over 50 organizations are on the ICC's email distribution list. One ICC priority is to ensure family engagement in the services provided to their children who are eligible for early intervention services and those at-risk. Three statewide ICC meetings and one retreat took place during FY2018.

The Council partnered with the Institute for Health and Recovery to support the capacity of and massFAS to address the unmet needs of families and the Fetal Alcohol Spectrum Disorder (FASD) population in Massachusetts. The overarching goals of massFAS are to implement FASD eligibility for state services; promote a comprehensive and accessible continuum of care for children from birth through 21, adults and older individuals with FASDs; to institute affordable evidence-based FASD interventions; to increase identification of individuals at risk of FASD so that FASD-informed services might impact their life trajectory; and to and promote parent/youth navigators and coaches. During FFY2018, Institute for Health and Recovery spent \$16,843 in Council funds and contributed an additional \$200 for this project.

The Council and massFAS collaborated to address 7 strategies: developing relationships with other disability and advocacy organizations, educating policymakers about the challenges and lack of services for the FASD population, determining eligibility for services for individuals with an FASD across the US, conducting training, education and awareness activities for stakeholders at

conferences and other events, improving social media and internet presence, attending FASD State Task Force meetings, identifying solutions to ensure the long term viability of massFAS,

In early FY18, a Council member led the effort to advocate for proposed legislation that would affect her daughter, a medically fragile child. The legislation was “An Act for the continuous skilled care of fragile children in the Commonwealth.” Council staff presented the bill to its policy committee which unanimously voted to endorse the bill, and directed staff to educate policymakers about the importance of this legislation. Council staff assisted the Council member in drafting testimony on the bill for a hearing in front of the Joint Committee on Public Health in October 2017, where 12 policymakers were educated about this issue. The Council member shared her story of her medically fragile daughter who has complex needs that must be met with continuous skilled nursing in their home. The lack of skilled nurses willing to do this work for the low rates provided creates an ongoing crisis for the families requiring these services. Over the next several months, Council staff, the Council member and members from the Massachusetts Pediatric Home Nursing Campaign met seven times with different Legislators to educate them on this issue. On July 31, 2018, the bill was amended and passed the Senate unanimously. It was moved to the House of Representatives for further action, but did not pass out of committee. The Council plans to continue its partnerships and efforts in educating policymakers about this important legislation in FY19.

The Council educated 16 policymakers on one of its Legislative priorities, An Act Providing Equal Access to Evaluations for Children with Disabilities. A parent council member submitted testimony about the importance of establishing reasonable rates for independent educational evaluations at a legislative hearing in December, 2017. The House bill was reported favorably to the Ways and Means committee, and the Senate version was sent to study.

The Council increased awareness about individualized family supports by sharing information with its hundreds of followers on Facebook and Twitter. There were 24 posts pertaining to this objective in FY18, double the target of 12 posts. The Council's top viewed post reached 2,009 people. It depicted a meeting with a State representative, Council staff and family members of massFAS advocating for supports and services for individuals with FASD. The massFAS Facebook page increased its audience by over 120 people for a total of 197 followers for FFY 2018.

The Supporting Families Coalition has a closed Facebook group with 413 members where family members of people with developmental disabilities and advocates can share helpful information and personal stories, and seek advice regarding their unique circumstances. Information was posted and shared frequently during FFY 2018.

During FFY18 Council staff, members, and partners educated an estimated 207 policymakers about individualized family supports, including legislators, legislative staff, state human service agency administrators and the Governor.

## 12. Expected Outcomes Achieved

Expected Outcomes	Achieved
Increased knowledge of families about family supports. Increased advocacy about family supports Increased knowledge of policymakers about supports.	true



**13. Progress towards achieving outcomes for overall objective : The annual report should include an assessment as to the extent to which progress was made on the intended outcomes for the objective.**

The expected outcomes for this objective were met: Increased knowledge of families about family supports, increased advocacy about family supports and increased knowledge of policymakers about supports. The Council will continue its work on this Objective in FFY2019.

**14. Additionally, include stories of culturally diverse people with developmental disabilities whose lives are better because of Council work on this activity (e.g., became better advocates for themselves and others, became more connected to the community). Stories of policy or legislative changes that happened as a result of Council individual advocacy work that are likely to positively impact the lives of people with developmental disabilities or that will prevent a potential negative impact (e.g., created deleted, refined programs and/or legislation, reallocated use of funds, organizational systems change as a result of evidence based practices).**

The Council supported two individuals and six 6 family members from MassFAS to meet with legislator's 4 times in FY18 to solicit support for legislation that would expand the definition of developmental disability in the state of Massachusetts to the federal definition. This would potentially result in some individuals with FASD being eligible for DDS services. Participants shared their personal stories of how the gap in support for individuals with FASD presents challenges in their everyday lives. One State Representative expressed her support but suggested that the group reach out to more prominent legislators in their efforts to file a bill changing the state's definition of

developmental disability to match the federal definition. The Council then assisted MassFAS to set up a meeting with a prominent State Senator. Subsequently, this meeting led to other meetings where the State Senator and a supportive State Representative agreed to co-sponsor legislation addressing this issue. A bill will be filed in January FY19.

## Individual & Family Advocacy Performance Measure

### Description

Supporting Families

### Race/Ethnicity

Race/Ethnicity	#	%
White, alone	33	62.26
Black or African American alone	1	1.89
American Indian and Alaska Native alone	0	0

<b>Race/Ethnicity</b>	<b>#</b>	<b>%</b>
<b>Hispanic/Latino</b>	4	7.55
<b>Asian alone</b>	10	18.87
<b>Native Hawaiian &amp; Other Pacific Islander alone</b>	0	0
<b>Two or more races</b>	1	1.89
<b>Race unknown</b>	4	7.55

Gender

<b>Gender</b>	<b>#</b>	<b>%</b>
<b>Female</b>	39	84.78
<b>Male</b>	7	15.22
<b>Other</b>	0	0

Category

<b>Category</b>	<b>#</b>	<b>%</b>
<b>Individual with DD</b>	10	3.12
<b>Family Member</b>	311	96.88

Geographical

Geographical	#	%
Urban	38	86.36
Rural	6	13.64

I. Output Measures

Objective	Performance Measure : IFA 1.1 People with DD who participated in activities	Performance Measure : IFA 1.2 Family members who participated in activities
A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.*	0	176
A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.*	10	135
Total # of Output Respondents	8	53

## II. Outcome Measures

<b>Performance Measures</b>	<b>Percent (%)</b>
<b>IFA 2.1 Percent of people with DD who increased advocacy</b>	75
<b>IFA 2.2 Percent of family members who increased advocacy</b>	74

Sub-Outcome Measures : The number (#) of people who are better able to say what they want/say what is important to them

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.*</b>	0	29
<b>A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.*</b>	6	24
<b>Total # of Sub-Outcome Respondents</b>	6	53

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>IFA 2.3 Percent of people better able to say what they need</b>	75	100

Sub-Outcome Measures : The number (#) of people who are participating in advocacy activities

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.*</b>	0	29
<b>A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.*</b>	6	24
<b>Total # of Sub-Outcome Respondents</b>	6	53
<b>IFA 2.4 Percent of people participating in advocacy activities</b>	75	100

Sub-Outcome Measures : The number (#) of people who are on cross disability coalitions, policy boards, advisory boards, governing bodies and/or serving in leadership positions.

<b>Projects</b>	<b># People with developmental disabilities</b>	<b># Family Members</b>
<b>A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.*</b>	0	0
<b>A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.*</b>	0	0
<b>Total # of Sub-Outcome Respondents</b>	0	0
<b>IFA 2.5 Percent of people on cross disability coalitions</b>	0	0

**IFA 3 The percent of people satisfied with a project activity\***

98.4

**IFA 3.1 Percent of people with DD satisfied with activity\***

100

**IFA 3.2 Percent of family members satisfied with activity\***

98.3

## System Change Performance Measures

### Description

Supporting Families



SC 1: Output Measures - The number of Council efforts to transform fragmented approaches into a coordinated and effective system that assures individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

<b>Objective</b>	<b>SC 1.1 Number of policy/ procedures created/ changed</b>	<b>SC 1.2 Number of statutes/ regulations created/ changed</b>	<b>SC 1.3.1 Number of promising practices created</b>	<b>SC 1.3.2 Number of promising practices supported through Council activities</b>	<b>SC 1.3.3 Number of best practices created</b>	<b>SC 1.3.4 Number of best practices supported through Council activities</b>	<b>SC 1.3 The number of promising and/or best practices created and/or supported</b>	<b>SC 1.4 Number of people trained/ educated</b>	<b>SC 1.5 Number of Systems Change activities with other organizations</b>
<b>A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.</b>	0	0	0	0	0	0	0	12	0

Objective	SC 1.1 Number of policy/ procedures created/ changed	SC 1.2 Number of statutes/ regulations created/ changed	SC 1.3.1 Number of promising practices created	SC 1.3.2 Number of promising practices supported through Council activities	SC 1.3.3 Number of best practices created	SC 1.3.4 Number of best practices supported through Council activities	SC 1.3 The number of promising and/or best practices created and/or supported	SC 1.4 Number of people trained/ educated	SC 1.5 Number of Systems Change activities with other organizations
A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.	0	0	0	4	0	0	4	368	2

Systems Change SC 2: Outcome Measures

Outcome Measures	Number(#)
SC 2.1 - Efforts that led to improvements *	0
SC 2.2 - Efforts that were implemented *	1

Sub-Outcome Measures

<b>Objective</b>	<b>SC 2.1.1 Policy, procedure, statute, regulation improvements</b>	<b>SC 2.1.2 Policy, procedure, statute, regulation implemented</b>	<b>SC 2.1.3 Number of improved promising or best practices</b>	<b>SC 2.1.4 Number of implemented promising or best practices</b>
<b>A minimum of 200 families will pursue the community resources available to support them and their family members with developmental disabilities by September 30, 2021.</b>	0	0	0	1
<b>A minimum 100 families will attain needed levels of individualized family supports to support them and their family member with developmental disabilities by September 30, 2021.</b>	0	0	0	0

## Section V: Council Financial Information

\* - Required input

### Council is its own DSA

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Yes

Fiscal Information for Programmatic Purposes ONLY

**1. Fiscal Year: \***

2018

**2. Reporting Period - Start\***

10-01-17

**2. Reporting Period - End\***

09-30-18

**3. Total Federal Fiscal Award for Reporting Year\***

1363306

**4. State Funds Contributing to Council State Plan Activities\***

357575.12

**5. Additional Council Funds Used for Other Activities\***

127263.91

**6. Federal Share of Expenditures\***

655234.31

**7. Federal Share of Unliquidated Obligations\***

220562.78

**8. Unobligated Balance of Federal Funds (=Total Federal Fiscal Year Award - Federal Share of expenditures - Federal Share of unliquidated obligations)\***

487508.91

**9. Match Required\***

139321.99

**10. Match Met\***

343432.74

**11. Match Unmet\***

0

Fiscal Information for Programmatic Purposes ONLY

**1. Fiscal Year: \***

2017

**2. Reporting Period - Start\***

10-01-16

**2. Reporting Period - End\***

09-30-18

**3. Total Federal Fiscal Award for Reporting Year\***

1399328

**4. State Funds Contributing to Council State Plan Activities\***

357237.97

**5. Additional Council Funds Used for Other Activities\***

174861.64

**6. Federal Share of Expenditures\***

1334346.5

**7. Federal Share of Unliquidated Obligations\***

22028.61

**8. Unobligated Balance of Federal Funds (=Total Federal Fiscal Year Award - Federal Share of expenditures - Federal Share of unliquidated obligations)\***

42952.89

**9. Match Required\***

140647.42

**10. Match Met\***

455268.05

**11. Match Unmet\***

0

Fiscal Information for Programmatic Purposes ONLY

**1. Fiscal Year: \***

2016

**2. Reporting Period - Start\***

10-01-15

**2. Reporting Period - End\***

09-30-18

**3. Total Federal Fiscal Award for Reporting Year\***

1394959

**4. State Funds Contributing to Council State Plan Activities\***

349546.75

**5. Additional Council Funds Used for Other Activities\***

171235.57

**6. Federal Share of Expenditures\***

1394959

**7. Federal Share of Unliquidated Obligations\***

0

**8. Unobligated Balance of Federal Funds (=Total Federal Fiscal Year Award - Federal Share of expenditures - Federal Share of unliquidated obligations)\***

0

**9. Match Required\***

111277.07

**10. Match Met\***

412925.01

**11. Match Unmet\***

0

**Dollars leveraged for the reporting year being reported\* 204111**

## Section VI: Measures of Collaboration

\* - Required input

**Identify the critical issues/barriers affecting individuals with developmental disabilities and their families in your State that the Council and the P&A, the Council and the UCEDD, the Council and other collaborators may have worked on during the reporting period**

The statewide self-advocacy organization has existed for nearly 20 years. However numerous barriers remain including becoming a truly independent board, and diversifying revenue to attain self-sufficiency. All four DD Network partners collaborated to support board and program development and expanding the self-advocacy network during FFY17. Developing and supporting self-advocate leaders remains a difficult process due to limited opportunities and a lack of resources to effectively support self-advocates in leadership positions. In FFY17 the Council and UCEDDs (Institute for Community Inclusion, Shriver Center) financially supported two year-long fellowships. Many people with developmental disabilities do not exercise their right to vote. On average, only 42% of people with all disabilities vote. A major barrier to voting is the belief, by both the service system and people with developmental disabilities, that they are prohibited from voting. In FFY17 the Council and the Disability Law Center's partnered in the RevUp MA initiative.

Identify the Area of Emphasis collaboratively addressed by DD Network

1. **Quality Assurance** true
2. **Education and Early Intervention**
3. **Child Care**
4. **Health**
5. **Employment**
6. **Housing**
7. **Transportation**
8. **Recreation**
9. **Quality of Life** true



**10. Other - Assistive Technology**

**11. Other - Cultural Diversity**

**12. Other - Leadership** true

**13. Other - Please specify**

**14. Other - Please specify**

**15. Other - Please specify**

Strategies Collaboratively implemented by DD Network

**The report should include a narrative progress report that cohesively describes the activities that were implemented by the Council and the P&A, the Council and the UCEDD, the Council and other collaborators.DD Network. For at least one of the issues/barriers identified above describe: (a) the issue/barrier; (b) collaborative strategies to address issue/barrier and expected outcome(s); (c) the DDC's specific role and responsibilities in this collaborative effort. Include any technical assistance expertise DD Council staff can provide to other States in this area; (d) briefly identify problems encountered as a result of this collaboration, and technical assistance, if any, desired; and (e) any unexpected benefits of this collaborative effort.**

The DD Network collaborated in multiple areas in FFY18. The three primary areas included supporting self-advocacy, leadership development and voting. In FFY18 the network, along with the state DD agency, continued supporting regional efforts to better link the local self-advocacy groups with statewide activities. The network partnership also continued funding for specific projects to be implemented by self-advocate employees.

The network continued collaboration to support strong community organizing and systems advocacy. The Council and the two UCEDDs (Institute for Community Inclusion, Shriver Center) financially supported two year-long fellowships in FFY18, one for a person with a developmental disability and one for a family member. These fellowships provided opportunities for the fellows to develop and enhance leadership skills and knowledge of disability issues and systems advocacy. The Gopen Fellowship is for a person with a developmental disability. The Crocker fellowship is for a family member.

In FFY18 the Council partnered with the Disability Law Center, Independent Living Centers and other advocacy groups in the RevUp MA initiative to continue educating people with disabilities, families, providers, voting officials and many others in an effort to increase participation of people with developmental disabilities in the election process.

The Council provided the technical staffing to manage and update the RevUp MA database and website. The website provides useful information and tools for voters with developmental disabilities. Improved strategies for the campaign to register voters were developed and implemented and the database was used to provide timely information to voters with developmental disabilities. Since the 2018 election was held in FFY19 follow up data on actual voting numbers was not yet obtained.